Coping, use forms, and learning levels

a copability analysis of DiasNet, a computer-supported disease management system for diabetes patients, focusing on adoption and empowerment

Boisen, Egil

Publication date:
2006

Document Version
Publisher's PDF, also known as Version of record

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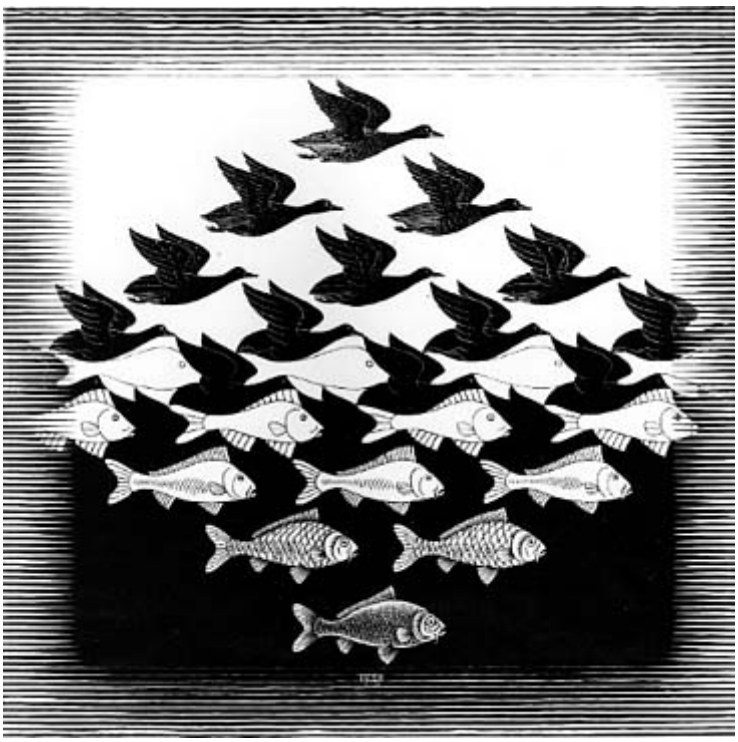

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2006

ISBN-13: 978-87-90562-54-0
ISBN-10: 87-90562-54-2

TIL PERNILLE, MIT VILDNIS,

OG VORES TOTALT VILDE UNGER

CONTENTS

Preface

In the beginning, I remember the uncomfortable feeling of facing chaos. From where I was sitting not much else was to face, anyway, being placed in the rear end of a class room watching a group of eight patients from behind as they were attending their first diabetes school session at Vendsyssel Hospital in Frederikshavn. The diabetes school was a part of the Diabetes Project, itself being a part of a huge system of projects called the 'Digital North Denmark' (in Danish, 'Det Digitale Nordjylland', DDN, 2000-3) looking into ways of exploiting ICT in the developing 'network society' of Denmark. The aim of the Diabetes Project was to implement DiasNet, a web-based medical decision-support system, as a telemedical disease management system for outpatients. My role as a PhD student (2002-5) was to monitor this project as part of the DDN monitoring research at Aalborg University. But what was I supposed to monitor? What was relevant to notice in studying the usefulness of DiasNet? I had no idea. I tried to keep my eyes wide open noticing all kinds of little details. But soon, creepy feelings of guilt and despair were building up: I was supposed to become a scientist. I was supposed to be in control! How could I possibly succeed not knowing what data to collect and why? However, this was only the beginning.

Now, at the end of the project, I wish to thank all the people who helped me along, first of all, my two supervisors providing me with loads of support, patience and space: Ann Bygholm, PhD, associate professor, Department of Communication and Psychology, Faculty of Humanities, Aalborg University (AAU), and Ole K. Hejlesen, PhD, associate professor and Head of Medical Informatics Group, Department of Heath Science and Technology, Faculty of Engineering, Science and Medicine, AAU.

Also, I wish to express my sincere appreciation to those who commented on earlier drafts of parts of this work, following the progression closely: Pernille Rishøj Boisen, psychotherapist; Dean Hayduck, psychotherapist; Helle S. Wentzer, PhD, assistant professor, Department of Communication and Psychology, AAU; Ellen Christiansen, PhD, associate professor, Department of Communication and Psychology, AAU; and Helena Lindgren, PhD student, Department of Computing Science, Umeå University. Additionally, I received much valuable comments from (in alphabetical order): Stig Kjær Andersen, PhD, associate professor, Department of Heath Science and Technology, AAU; Jytte Brender McNair, PhD, associate professor, Department of Heath Science and Technology, AAU; Lone Dirckinck-Holmfeld, PhD, research professor, Department of

Communication & E-Learning Lab, AAU; Pia Britt Elberg, assistant professor, Department of Heath Science and Technology, AAU; Peter Elsass, DMSc, professor, Centre for Humanistic Health Research, Department of Psychology, University of Copenhagen; Gitte Engelund, Oticon A/S Research Centre Eriksholm; Mariane Hedegaard, PhD & Dr.Phil, professor, Department of Psychology, University of Copenhagen; Bibi Hølge-Hazelton, PhD, Research Unit for General Practice, University of Copenhagen; Victor Kaptelinin, PhD, professor, Department of Informatics, Umeå University; Klaus Kaasgaard, PhD, director of user experience research, Yahoo; Thomas Lunner, PhD, associate professor, Oticon A/S Research Centre Eriksholm; Peter McNair, MD, Director of EHR Development, Copenhagen Region; and Etienne Wenger, PhD, honorary professor, AAU. My deeply-felt gratitude goes to my friends and mentors for their internalised voices: Bjørn Lomborg, Claus B. Mandøe, Jens P. Haase, Dean Hayduck, Morten Carlsen, Steen R. Bjerg, and Stig Dankert Hjort. To my family: thanks for all your annoying questions concerning the completion of this work, and I apologise for being so caught up in my thoughts. Doing science may include not losing sight of the real world for too long!

In taking care of the many practical matters entailed in this project, I received much help from: Else Ramsgaard, information officer, Department of Heath Science and Technology, AAU; Birthe Dinesen, PhD student, Division of Technology, Environment and Society, Department of Development and Planning, AAU; Søren Plougmann, PhD student, Department of Heath Science and Technology, AAU; Aase Andersen, head of department secretary, Department of Communication and Psychology; and Kevin Petersen, IT consultant, Danish Employment Service, The County of North Jutland. I also wish to thank the medical staff at Vendsyssel Hospital, Dorthe Bach Andersen, nurse; Britta Nedergaard, nurse; Kurt Clemmensen, consultant; Mette Birkkjær, secretary; as well as the medical staff at The Royal Bournemouth Hospital, Joan Everett, nurse; Emma Jenkins, nurse; Dr David Cavan, consultant diabetologist; and Clare Shaban, clinical psychologist. And last but not least, I very much appreciate the help from each of the nine patients in this study – please find your pseudonym in the appendix!

Egil Boisen, Aalborg, October 2006

1 Evaluating DiasNet as a disease management system for IDDM patients

1.1 Introduction: The challenges of diabetes mellitus

Diabetes mellitus is a clinically complex disease characterised by a metabolic disorder due to a defect in insulin secretion or action. It is a one of the major chronic diseases and a growing public health problem in both developed and developing countries (DCCT, 1993). Diabetes' estimated direct costs in the USA in 2002 were US$ 91.8 billion (American Diabetes Association, 2003), while contemporary global estimates show that direct costs of diabetes range from 2.5% to 15% of annual health care budgets (WHO, 2002) – the indirect costs being even higher. It is estimated that in the year 2000 the excess mortality related to diabetes was close to 3 million deaths (Roglic et al., 2005), i.e., a vast number of premature deaths when the people concerned are economically contributing to society. Furthermore, it is associated with a substantial loss of quality of life, on the one hand, due to the impact on everyday life from both treatment and the risk of suffering from acute conditions, and on the other hand, due to the risk of developing late complications, such as blindness, kidney failure, amputations and cardiovascular complications. Also, several studies suggest that diabetes doubles the risk of depression compared to those without the disorder (Anderson et. al., 2000).

In insulin-dependent diabetes (IDDM) there is little or no remaining endogenous insulin production. Insulin is responsible for the absorption of glucose in the cells. A constant and balanced supply of insulin is therefore indispensable. A lack of insulin leads to an excess of blood glucose, hyperglycaemia, which may develop into an acute condition of ketoacidosis, both being very unpleasant and potentially fatal. At the other hand, an IDDM patient having more insulin than necessary in the blood will suffer from an immediate drop in blood sugar level, and may thus be alarmed by unpleasant ‘feelings’, such as sweaty palms, shakiness, fatigue, anxiety, headaches, difficulty concentrating, and excessive hunger. If not treated properly this may also develop into an acute and potentially fatal condition of a critically low blood sugar level, hypoglycaemia, in which the patient may suffer from loss of motor control or consciousness. Finding the balance is not an easy task. The blood glucose level is dependent on a number of factors apart from insulin, prominently the intake of carbohydrate, but also the amount of exercise, warm weather, stress, illness, travelling, menstruation, intake of alcohol – in short, many aspects of everyday life. In diabetes, therefore, the vast majority of healthcare decisions

are in the hands of the patient. Hence, a number of studies show evidence in favour of considering active self-care a cornerstone of diabetes management (Cavan, 2001; Corbett, 2001).

1.1.1 The challenge of the DCCT as a landmark trial

In 1993 it was shown in the Diabetes Control and Complications Trial (DCCT) that intensive insulin therapy (IIT) with the goal of maintaining blood glucose concentrations close to the normal range can markedly reduce the incidence of many complications (DCCT, 1993), compared to 'conventional' treatment. In the DCCT study, conventional insulin treatment in the control group was consisting of only one or two insulin injections daily as well as a strict meal plan, while in the experimental group insulin was delivered either by pump or administered as three or more insulin injections per day. Also, the patients were allowed to modify their dietary plan themselves when adjusting the insulin accordingly (DCCT, 1988). This landmark trial has set a standard for modern treatment of diabetes type 1.

However, the DCCT studies have also shown that intensive insulin therapy was associated with an excess weight gain, and a three-fold greater risk of episodes of hypoglycaemia, compared to conventional therapy (DCCT, 1995). Furthermore, an increase in therapy planning complexity and resources needed are obvious drawbacks (Glasgow et al., 1996, Gomez, 1996; Lehmann, 1997a,b; Belazzi et al., 2002). In the DCCT, patients in the intervention group were seen fortnightly and often contacted by telephone weekly, and the treatment expenditures where three times higher than normal treatment. In addition, IIT implies a significant increase in the amount of data to be monitored and processed. In intensive treatment the Type 1 diabetic patients have to perform a strict daily self-monitoring of blood glucose (SMBG) level, by measuring it before every injection, and by recording the data on hand written diaries, together with the amount of insulin injected, and with additional information about diet and life style. Firstly, the workload and life style management that is required implies a considerable amount of patient motivation, and this has proven to be an Achilles' heel of IIT, especially in established patients (Glasgow et al, 1996). Furthermore, it is questionable whether most physicians have the time or the skills to provide self-management interventions to patients, particularly in the area of lifestyle changes (McKay, 2002). What is more, the potential advantages of this new patient monitoring regime may be limited by the way doctors and patients relate to the huge amount of self-monitoring data (Gomez et al, 1996; Belazzi et al., 2002). The communication between doctor and patient about the data is normally restricted to periodical control visits being scheduled every 3 – 6 months. Meanwhile, the patients use self-monitoring data to manage

day-to-day therapeutic decisions. However, the epidemiological burden and the doctors' workload restrict the visit time assigned to each patient (Gomez et al., 2002). For these reasons, it is difficult for doctors to assist patients in day-to-day decisions, and at the same time, it is difficult for patients to assist doctors in analysing the data on a visit-by-visit basis, because it is difficult to remember all the relevant details that may influence the data, such as the variations in every day life.

1.1.2 The challenge of disease management and patient empowerment

The increasing recognition of self-care as a cornerstone in diabetes care has forced the medical establishment to understand the potential for active patient involvement and patient autonomy in chronic disease management (Montori & Smith, 2001). In trying to illustrate the difference between traditional medicine and the disease management approach, Kate Lorig (2001) identifies three models of care by way of a metaphor: Traditionally, within the old medical model of care, doctors are trained to 'pull a patient out of the river of illness', whereas the public health model tries to prevent the patient from 'falling into the river', through vaccinations and campaigns against smoking, heart diseases, HIV, and so forth. As opposed to these two models, the disease management model is dealing with chronic illnesses and therefore oriented towards teaching people how to 'swim'. This new model of care presents both patients and health care professionals with huge challenges, which I will discuss in what follows.

Concerning the patients' challenges, I will discuss three aspects: Knowledge, motivation, and patterns of response to emotional stress in living with diabetes. Firstly, in order to play a significant role in disease management, the diabetes patient needs basic knowledge about diabetes treatment, such as hygiene, foot care, urine testing, injection techniques, insulin reactions, management of intercurrent illness, etc. (DCCT, 1988).

Secondly, another aspect has to do with patient motivation and the differences in perspectives of the patient and health professionals. It is not only a matter of informing the patient about 'the right thing to do', because the readiness in adjusting behaviour depends on the patient's evaluation of the perceived threat and the costs and benefits of altering behaviour (Weiss, 2001). Thus, important aspects of this problem might be deviating perceptions of health threat, or that the perceived costs might overshadow the benefits. Poor metabolic control does not necessarily prevent the patient from feeling great. In some studies, IDDM patients with poor metabolic control expressed more experience of well being than those with good metabolic control (Weiss, 2001; Lundman, 1990). Also, it might not be easy for the diabetic patient to understand the health threat

of late complications (Lundman, 1990). In addition, the patient is likely to have a different view of the costs of compliance. Fear of hypoglycaemia has been reported as a major reason for poor metabolic control (Mollema et al., 1998), which is quite understandable as good metabolic control increases the risk of hypoglycaemia (DCCT, 1994).

Thirdly, the patient's response to emotional stress in living with diabetes has been the subject of increasing attention. One problem has to do with perceived stigmatisation, as diabetics often fear stigmatisation because the illness is closely linked with obesity, or because the illness in itself or its symptoms may be seen as a physical weakness that requires special attention from others (Wolfer, 2003; also expressed in several interviews with the patients in this project: 'Jens', 'Karsten', 'Morten', and 'Per'). In effect, in trying to hide away the fact that they have diabetes, patients suffering from a fear of stigmatisation may face increased difficulties in taking good care of their illness, e.g., while being at work. Another example of this kind of problems is that some patients compare themselves to the 'perfect diabetic' and may therefore be at risk of developing a counter-productive emotional response when facing problems of living up to this ideal, such as feelings of guilt and in some cases tedium, a burn-out syndrome among patients (Corbett, 2001; Weiss, 2001; Lundman, 1990; Everett, 2001).

Arguably, a fourth aspect of the patients' challenges is the doctor-patient relationship and managing the health care system, as will be clear in what follows concerning the doctors' challenges.

One central issue concerning the doctors' challenges in chronic disease care has to do with the structure of health care work. 'The old medical model of care' is oriented toward providing optimal care for people with acute illnesses through single, brief, unplanned, and unscripted consultations with limited follow-up, and with brief and focused education (Montori & Smith, 2001; Paterson, 2001). Chronic disease management, at the other hand, may be defined as a non-episodic system of coordinated health care interventions and prevention activities (Hunt et al., 2001), in conditions where self-care efforts are significant (DMAA, 2006). Another important issue concerns what it means to ensure that a patient learns to 'swim'. Here, the doctors are in deep waters together with their patients! When a patient is saved from the immediate risk of 'drowning', then who is to determine whether the patient is doing well or not? Diabetes and everyday life of the patient are heavily interrelated, and this may lead to a conflict between management of the disease, and the person's total goal in life (Lundman, 1990). Studies indicate that to ensure a constructive doctor-patient relationship, it is important not to overrule the patient's perspectives (Lorig, 2001; Weiss, 2001). Doctors, however, are trained to

diagnose 'diseases' as somatic entities within the patients' bodies – they are not trained to be concerned with 'health', or to work with the patient as a whole taking into consideration the patient's thinking, family situation, working life, motivation, etc. (Juul Jensen, 1995). In other words, asking only clinical questions will only provide answers about the patients' diseases, not about their health. The disease management approach thus presents the doctor with the challenge of reflecting on the overall goal of the treatment as well as his or her attitude toward the patient. Gibson claims that it entails a 'radical paradigm shift' within health care to accept that, basically, patients are responsible for their own health, and that health professionals need to develop new skills in order to accommodate to a change of roles (Gibson, 1991). Also, as stated by 'DESG', a section of a European association for the study of diabetes:

> A shift must be made from the traditional, authoritarian, paternalistic attitude, to an attitude of full acceptance, empathy, and encouragement to share the responsibility of treatment choice and day-to-day implementation. (Maldonato et al., 2001)

To sum up, IDDM care involves more than merely working out an adequate regime. To make chronic disease management work, the patient needs motivation for the necessary life-style changes, to gain a great amount of knowledge on how to do so, and to keep up the good spirits in order not to be demoralized. In addition, the structure of disease management processes and the idea of taking account of the patient's perspective imply tremendous challenges for the doctors concerning the nature and the structure of health care delivery services.

During the past twenty years, chronic disease care and patient education has evolved from its medically-dominated and narrow origin in patient teaching to support 'patient empowerment' (Gibson, 1991; Feste & Anderson, 1995; Anderson, 1996; Rodwell, 1996; Glasgow et al., 1999 a, b; Roter, 2001; Anderson & Funnel, 2005), i.e., treating the patient as an active and autonomous subject instead of merely a passive object of health care. In a much-cited article, Gibson defines empowerment as:

> 'a social process promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources to feel in control of their own lives. Even more simply defined, empowerment is a process of helping people to assert control over the factors which affect their health.' (Gibson, 1991)

Empowerment as a concept stems from the Latin word 'potere' (meaning to be able), and in its dictionary sense it is described as permitting something, or as enabling, or giving power/ authority/ ability to someone (Gibson, 1991). As a concept within chronic disease care and patient education, however, it is rooted in social action ideology, with the civil rights

movement and the women's movement of the 1960's, and the growing consumer and self-help movement in the 1970's, which converged in advocacy for greater social equity (Gibson, 1991; Roter, 2001), while it was finally brought into a nursing context in the mid-1980's by WHO and 'The Ottawa Charter of Health Promotion', emphasising both lifelong learning and the enhancement of individual life skills (Gibson, 1991; Roter, 2001; WHO, 2006).

The concept of empowerment is thus founded on an emancipation discourse. Within chronic disease care and patient education, this is motivated by a dichotomy between two perspectives, a medico-centred and a patient-centred perspective, as illustrated by the model below (see Table 1.1, adapted from Skelton, 1997, referring to Fahrenfort, 1987, which does not, however, contain this model). Whereas the traditional medico-centred 'compliance approach' to patient education may reinforce powerlessness and helplessness, as it is designed to reduce patient autonomy and constrain freedom of choice, the empowerment approach, in contrast, is focused on helping patients in developing self-awareness about their own health values, needs, and goals in order to function as equal and autonomous members of their healthcare team (Feste & Anderson, 1995).

Medico-centred	Patient-centred
Compliance	Autonomy
Adherence	Patient participation
Planning for patients	Planning with patients
Behavior change	Empowerment
Passive 'patient'	Active 'client'
Dependence	Independence
Professional determines needs	Patients define needs

Table 1.1: Two principal models of patient education, the medico-centred and the patient-centred (Skelton, 1997, building on Fahrenfort, 1987).

This new approach to patient education has some of its theoretical underpinnings in the work of Paolo Freire (Freire, 1973/ 2005) and his participatory learning strategies (cf. Wallerstein & Bernstein, 1988; Roter, 2000; Roter, 2001). Freire suggested that 'treating people as active subjects can have the effect of changing patterns of dependence and passivity by providing participatory learning experiences fostering the competence and confidence necessary for personal transformation and the realization of critical consciousness' (Roter, 2001). According to Roter (2001), Freire identified three key consciousness raising experiences from which

such a personal transformation may follow: Relating and reflecting on experience, exploration and problem solving, and taking thoughtful action. Giving diabetes care as an example, Roter explains the three levels the following way (cf. Roter, 2001):

- Relating and reflecting on experience: inclusion of patient's preferences; disclosure of the patient's illness narrative.
- Exploration and problem solving: Active inquiry and investigation into conditions and circumstances that may contribute to a medical problem or may be useful in treatment and management.
- Taking thoughtful action on one's own behalf: choice, control and responsibility for treatment.

Concerning the current success of this approach within diabetes care, a recent review has shown that patient education programs have increased emphasis on the patient's role and responsibility, and that several interventions have reported strong and wide-ranging effects including improvements in self-efficacy, self-management, metabolic control, patient satisfaction, and quality of life (Glasgow et al., 1999a). The downside to these findings, however, is that the concept of empowerment is not often used in accordance with the thinking described above, but instead is used as interchangeable with concepts like self-efficacy and with an overshadowing focus on adherence (Glasgow et al., 1999a). Thus, a number of studies, which claim to be based on the empowerment approach, seem to be based on a targeted behaviour change strategy focusing on barriers to adherence/ compliance[1]. Also, a recent review exemplifies the prevailing medico-centric approach even when advocating a new model of care supporting active patient participation using the term 'empowerment' (Montori & Smith, 2001). While claiming to 'describe the past and current forms of communication and clinical information transfer dedicated to

[1] To give some examples found in the literature review to be reported on shortly: Firstly, Glasgow and colleagues have presented an ICT system to facilitate discussions between patients and health professionals that address behavioural issues, such as 'barriers to dietary adherence', and goal setting (Glasgow et al., 1995). Next, Solberg and colleagues (1997) mention empowerment in their IDEAL (Improving care for Diabetes through Empowerment, Active collaboration, and Leadership) Model of diabetes care, being based on 'planned change' and focusing on a reduction in HbA1c. And finally, Williamson et al. (2000) mention empowerment in relation to studying how to 'change self-efficacy and self-care attitude in order to overcome barriers to compliance/ adherence, e.g., through giving information, or patient-tailored goal-setting being sensitive to cultural, ethnic, and financial constraints in the patients lives'. Furthermore, a 1995 guideline on diabetes care in IDDM patients intended for physicians is not mentioning the empowerment approach at all (Caro, 1995).

improving the delivery of diabetes care', this review does not describe systems for patient use. Even though it emphasises the exit of the old medical model and the importance of supporting active patient participation in diabetes care, it only focuses on doctor-oriented systems in terms of data management systems to support a non-episodic system of coordinated multidisciplinary health care interventions and prevention activities. Interestingly, it reads:

> [T]he realization that [..] active patient participation may lead to improved adherence to best practice has led to the implementation of support structures toward self-efficacy: diabetes nurse educators providing individualized and culturally appropriate information and group education are just two examples of such support. (Montori & Smith, 2001)

Another study discusses the empowerment approach as being a mere 'myth' within diabetes care, and that it is sometimes even being used to justify paternalistic practices (Paterson, 2001). This study shows that, while claiming to be practicing the empowerment approach and to be welcoming of patient participation in treatment decisions, doctors do not 'walk their talk', as they are likely to behave in ways that implies professional dominance, e.g., by discounting a patient's experiential knowledge, or by quizzing the patient when he or she proposes and adjustment to the treatment, or even by accusing the patient of lying about the diet or SMBG (Paterson, 2001). Furthermore, yet another study has shown that doctors and nurses participating in an empowerment project felt that it was difficult to adjust to their new role of being a 'facilitator', and that it was easy to fall back on their traditional role of being an 'expert', even though they agreed with the new approach intellectually (Adolphson, 2004).

In a recent essay looking back on their 16 years of experience with promoting the empowerment approach within diabetes care, Anderson & Funnel (2005) explain such difficulties in terms of a battle between two scientific paradigms in the Kuhnian sense, i.e., a battle between, on the one hand, the acute care model that the health professionals has adopted during their training, and on the other hand, the new paradigm of empowerment and patient-centred collaborative diabetes care. They point out that such paradigm shifts can take a generation, because this development not only is a matter of acquiring a new set of skills or a new piece of technology (i.e., something that one is able to see/ focus on), but instead is a matter of altering a 'a psychological ''eye'' with which we see the

world but which we cannot see' (Anderson & Funnel, 2005)[2]. Thus, the old paradigm not only has a deep hold on one's thinking. It is likely to defy the new paradigm, because its outcome is judged in terms of the old one. As they explain:

> For example, after giving a presentation about empowerment, it is not uncommon for a health care professional in the audience to ask ''but will it improve patient compliance?'' (Anderson & Funnel, 2005)

To sum up, studies like these point to various cultural difficulties of implementing the new model of care within health care. In addition to these cultural difficulties, the empowerment approach is also facing criticism from a philosophical angle concerning its underlying emancipation ideology. Åkerstrøm Andersen, writing about empowerment as an upcoming paradigm within social work in Denmark, points out that contrary to how the new ideology appears on the surface, it is to be conceived of as a paternalistic approach deep down. While empowerment interventions set out to make people 'responsible', ironically, this implies that the subjects are considered as 'non-responsible' to begin with (Åkerstrøm Andersen, 2003). Building on Luhmann, Åkerstrøm Anderson explains that there is a (dialectical) unity of freedom and obligation, since the concept of obligation implies the freedom to choose. And while the empowerment intervention at a deeper level aims at making the subject free to choose their obligation, this implies that they are considered non-free individuals to begin with. In other words, to empower somebody you may first have to dis-empower the subject, which corollary becomes an 'object' of this process. As a logical consequence, one may add that the empowerment intervention makes it illegitimate for the subject not to feel responsible for his or her situation.

Concerning health care, one may ask, what does the notion of a 'paradigm shift' really mean? If the empowerment approach is not merely a new system of methods to obtain certain traditional values, such as the somatic health of the patient, but instead is asserting a new set of core values, such as 'sharing responsibility' or 'making the patient responsible', does this mean that the doctors should start concentrating on these core values at the expense of somatic health? Put in a provocative way: In trying to share responsibility with the patient, is it the case that the health care system becomes neither medico-centred, nor patient-centred, but ideology-centred instead?

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[2] This difference between learning a new skill and learning a new way of looking at one's activities (to learn new skills) is an example of a difference in 'learning levels', as we will be looking into more closely in chapter 3.

In line with this thinking, another recent critique has addressed the underlying dichotomy between the medico-centred and the patient-centred perspectives. Skelton, working within the field of low back pain, observes that while it is true that not all doctors and nurses are 'walking their talk', it is also true that patients are likely to accept the traditional roles:

> 'We are left with the apparent paradox that patients choose freely to behave in ways that ultimately control themselves.' (Skelton, 1997)

Skelton thus argues that the suggested dichotomy between a medico-centred and a patient-centred perspective is too narrow, and that what is needed is 'a new way of thinking and talking about patient education which transcends the restrictions imposed by this dichotomy' in order to integrate compliance-focused and empowerment-focused approaches (Skelton, 1997). Maunsbach, writing about patient education within diabetes care, also discusses this dichotomy and similarly argues that the two perspectives should be integrated. It would be meaningless for the patients to turn their back on the medical knowledge. If they didn't take their insulin, for instance, they would soon die. At the other hand, because various choices of disease management strategies are much like questions of lifestyle and various life goals, neither is it meaningful for the patient to let the doctor control every aspect of the disease management. Therefore, she concludes, the goal of empowerment is to provide the patient with more knowledge and better tools in order to have as much influence as possible on the choices made in the disease management process (Maunsbach, 2002).

Finally, the emancipatory potential of the empowerment approach has also been criticised from a political angle as favouring the resourceful citizens at the expense of the marginalized groups, whose views may not be heard in this debate (Anderson, 1996). Anderson thus observes that the professionals who make the decisions about policies and priorities within health care are likely to 'be more attuned to needs that arise among the types of people they know best, i.e., other people with power and privilege in society'. She further states:

> Until we unmask the unquestioned and taken-for-granted ideologies that are at the foundation of movements like self-care, and that are interwoven into seemingly liberatory ideas like empowerment, we will continue to produce "recipes for health and health care delivery" that privilege those who are already privileged, and disenfranchise those who are dispossessed. (Anderson, 1996)

This critique is based on Anderson's observation that the empowerment movement draws upon an individualistic and liberal ideology within Western thinking. While this may be the case concerning the adoption of empowerment ideas within a Western society, it is hardly in alignment

with the seminal thoughts of Freire and his principles of participatory learning, which more resembles a learning tradition building on the Marxist psychologist Vygotsky (to be discussed in chapter 3). Nevertheless, it seems a reasonable fear that the empowerment approach may turn self-care into do-it-yourself-care, or that this approach may be motivated by the lack of resources within the health care system as a good excuse to save time and money by releasing some of the burden from the doctors' shoulders while passing it on to the patients instead. As stated by Anderson:

> The real concern is that the politicization of "empowerment" could provide the rationale for "off loading" of responsibilities to people who have been made vulnerable through illness, who have few resources, and who are least able to assume the responsibilities that the empowerment movement suggests. (Anderson, 1996)

To sum up on the challenges of IDDM, active patient involvement is a cornerstone in intensive treatment of the disease. However, the patients are faced with a number of difficult problems in terms of acquiring new knowledge and skills, in terms of integrating diabetes care into their overall life goals, and in terms of handling emotional stress. What is more, the magnitude of the problem and the nature of chronic disease care is presenting the traditional health care system with a great variety of challenges, from a lack of resources in terms of time and money, to questions concerning ideological and cultural aspects of Western health care and a political debate on how this should develop in the future. Within this ongoing debate, 'patient empowerment' is a frequently used term, while the proper use of this concept and its influence on the actual delivery of health care services is a highly complex question. What seems to be a safe conclusion is that 'empowerment' can be understood as an approach, which conceives of the individual patient as more than merely an 'object' of health care, and which emphasises collaboration between patients and health professionals in a way that deviates from a traditional focus on compliance and adherence. It still remains debatable whether this deviation is to be understood in complete opposition to traditional aspects of Western health care, or as a 'middle way' between a patient-centred and a medico-centred approach. What seems certain, however, is that the concept is connected to patient learning that entails many more aspects than merely acquiring basic disease management skills.

In what follows, focusing on patient support, I will look at ways in which ICT has been employed in order to face these challenges, before turning to a presentation of my research questions in evaluating an ICT system to support active patient participation in IDDM care.

1.2 Literature review: ICT systems supporting IDDM care

Since the results of the DCCT in 1993, there has been a call for employing ICT to support active patient-participation in IDDM care. To review current literature on ICT systems research and development projects in IDDM care, a systematic review of peer-reviewed literature was conducted between 11 June 2004 and 17 June 2004 where the following six bibliographic databases were consulted: Medline, ISI Web of Science, Ingenta, Eric, Psychinfo, and SOC Abstracts. The search terms were defined by looking up the thesaurus resource in each database, when available, and a search expression consisting of the following three groups of search terms was used: ("Diabetes Mellitus, Type I") AND ("Disease Management" OR "Managed Care Programs" OR "Patient Care Planning" OR "Self Care" OR "Models, Nursing" OR "Nursing Research" OR "Holistic Nursing" OR "Chronic Disease" OR "Preventive Medicine") AND ("Therapy, Computer-Assisted" OR "Decision Making, Computer-Assisted" OR "Computer-Assisted Instruction" OR "Internet" OR "Telemedicine" OR "Decision Support Systems, Clinical" OR "Communications Media" OR "Medical Informatics" OR "Ambulatory Care Information Systems"). (In Medline, the terms were used as MeSH terms, and in particular the term “Diabetes Mellitus, Type 1” was formulated as ‘a major topic with no expansion’, in order to make sure that this was a focal issue of the articles, while the other two groups of terms were allowed to be only periferically related to the articles). A total of over 200 articles were identified and requested, of which a sample of 56 articles were selected to further limit the scope of the review to cover: scientific articles a) published in the decade since the DCCT (from 1994 to 2004), and b) focusing on computer generated, or mediated, information for patients and health professionals. The following review has the goal of providing an overview of systems approaches, while also being fairly detailed concerning experiences with ICT systems supporting active patient participation in IDDM care.

Three basic approaches were identified (inspired by Gomez, Pozo, & Hernando, 1996), being doctor-oriented system, patient-oriented systems, and integrated doctor and patient-oriented systems. Among these three approaches, five categories of systems were identified:

- Data management/ EMR (doctor-oriented systems)
- Decision support (primarily doctor-oriented systems)
- Computer assisted learning (primarily patient-oriented systems)
- Telemedicine (integrated doctor and patient-oriented systems)
- Social support (patient-oriented systems)

While this list categorises the focal functionality of the systems, it may also illustrate the historical development of purposes of deploying ICT within diabetes care, from doctor-oriented systems to integrated doctor and patient-oriented systems. Yet, what will be clear in what follows, current research on ICT systems supporting active patient participation is quite limited.

Data management/ electronic medical record (EMR): including systems for the collection, storage and retrieval of patient data, as well as quality control.

One of the earliest examples, which is also one of the earliest examples of ICT systems within diabetes care, is the 'Diabeta' system, which was first presented in 1973 (Belazzi, 2003). In spite of this early enterprise, the only two successfully implemented data management systems for diabetes care being reported on in the literature sample are the Diabetes Electronic Medical Record and Management System (DEMR and DEMS), which has been used within the Mayo Health System since 1993 (Montori & Smith, 2001), and the Diabetes Care Systems (DCS) being employed within the Kaiser Permanente organization (Domurat, 1999), both being implemented within large American non-for-profit health care organizations as doctor-oriented systems helping in keeping track of patient data from all interactions involving care of patients. One of the main reasons for the scarcity of successful diabetes EMR systems is the need for integrating such systems within hospital information systems and, in turn, the need for standardization of medical concepts and terminology, as well as interchangeable data formats (Belazzi, 2003).

As patients are becoming more active, the development of sharable consumer health records is crucial (Clerco, Hasman, & Wolffenbuttel, 2003). However, patient-oriented consumer health records to support self-directed disease management are rare. Generally, patients are not typically counted among the primary users of EMR systems (Winkelman & Leonard, 2004). This may be exemplified by the above-mentioned review by Montori & Smith (2001). Hence, there tend to be structural constraints embedded in the EMR systems that limit use by patients (e.g., structured entries, instead of unstructured free-text preferred by most patients; Winkelman & Leonard, 2004). Other problems concern the patients' ability to understand the data presented in the system, and the validity of data entered by the patient (Clerco, Hasman, & Wolffenbuttel, 2003). I will look more into the experiences with patient-oriented data management systems in the review of telemedicine and surveillance systems below.

Decision support: including electronic versions of paper-based clinical guidelines to support patient communication during visits, as well as

more advanced systems for data analysis and visualisation to interpret home monitoring data, and knowledge-based decision-support tools for therapy revisions.

The traditional medium for physician decision support is the clinical practice guideline (Hunt et al., 2001). In the literature a number of examples are found of intranet-based EPR integrated systems, which provide an electronic version of clinical guidelines: 'SCAN Personal Care Planner™' (Peterson, 1999), 'Logician' (Hunt et al., 2001), 'DCMSS' (Baker et al., 2001), 'DEMS' (Gorman et al., 2000; Montori et al., 2002). In addition, such systems may provide performance reports (Baker et al., 2001). In all cases, these systems are devised as 'visit-by-visit' systems to assist health professionals in patient communication, while having an underlying approach that is closer to a traditional focus on patient compliance and adherence than a patient empowerment approach.

More advanced decision support systems are developed to help in analysing the vast amount of patient data (primarily SMBG), being one of the focal challenges of intensive insulin treatment mentioned above (Lehmann, 1994). The majority of decision support systems are devised as doctor-oriented visit-by-visit systems for insulin-dosage adjustment (cf. Lehmann & Deutsch, 1995; Lahtela et al., 2002). One of the first examples is the UTOPIA system, originally designed to be integrated with Diabeta, provides physicians with a collection of modules for data analysis and visualization, extraction of blood glucose trend, and therapy revision (Deutsch et al., 1996). An older review of decision support systems mentions a single system for diet planning, DIACRONO, and a dozen for insulin-dosage adjustment, DiaComp, IDC, ExDiabeta, DIABETEX; DIAMON, AIDA, SESAM-DIABETE, AIDA, KADIS, 'Diabetes Simulator', and DIASIM (Lehmann & Deutsch, 1995). And while the first three systems mentioned are designed for patient use, the rest in this list are doctor-oriented. However, there has been a lack of integration of such systems into hospital systems, and few are under development at the present time (Belazzi, 2003). One of the main reasons for this lack of success has been difficulties in developing applications which are able to provide patient specific advice and can justify their reasoning (Lehmann, 1997b). Two main strategies have been followed, being the development of model-based simulators on the one hand, and rule-based advisory systems on the other hand. Among the limits of model-based reasoning (MBR) systems, on the one hand, is the lack of availability of data, such as for example the meal intakes (Lehmann & Deutsch, 1995), the quality of SMBG data (Lehmann, 1994), and the lack of validated models (Tatti & Lehmann, 2003). On the other hand, rule-based reasoning (RBR) systems face difficulties in special situations where the rules do not apply (Mon-

tani et a., 2000, 2003), such as the 'Somogyi effect' in not well stabilised patients, which shows as an endogenous counter regulation in terms of elevated blood glucose levels following hypoglycaemia (Lehmann, 1994 & 1997b; Montani et al., 2003; also implicitly referred to in Paterson & Thorne, 2000). Therefore, following the classic RBR approach, it would be necessary to device a complex rule system, involving meta-rules or context-dependent parameterised rules, and to progressively enlarge the rule base, up to intractable dimensions (Montani, 2003). Therefore, Montani, Belazzi and colleagues have recently proposed a multi modal-based (MMB) approach in the T-IDDM system integrating case-based reasoning (CBR) in order to take account of situations in which the knowledge embedded in the RBR and MBR modules do not apply (Montani et al., 2000 & 2003; Belazzi, 2003). Their model, however, is not able to capture phenomena such as the Somogyi effect and will therefore be mainly devoted to automatically keeping track of the current situation of each patient, to identify problems and to automatically provide suggestions only in simple cases, while alarming the health care professionals to deal with the complex situations (Montani et al., 2003). Such systems may help in saving time (Montani et al., 2003), being one of the other focal challenges mentioned above.

Computer assisted learning (CAL): including more or less simple interactive multimedia applications replacing printed information, Internet-based discussion groups, and more advanced model-based games for children and interactive diabetes simulators.

Among simpler systems is a touch screen system devised as an office-based intervention to assist in targeted behaviour change by prompting both patients and health professionals to address behavioural issues, such as 'barriers to dietary adherence', and 'goal setting' (Glasgow et al., 1995). This kind of patient education interventions is instantiating an empowerment approach being oriented toward integrating patient views on self-management and quality of life, however with a focus on (dietary) adherence. More recently, Glasgow, McKay, and colleagues (McKay et al., 1998; Glasgow et al., 1999a-b; McKay et al., 2002) have been looking into the potential benefits of an Internet-based disease management system, D-Net, consisting of three major components: Diabetes specific articles, a social support conference, and a database in which participants could enter their daily SMBG and receive graphic feedback. Experiences with D-Net focusing on social support will be discussed in the final section of this review. Furthermore, as a final example of simple systems is an online resource centre for health professionals, 'DESG', providing a system of educational material on various issues of diabetes disease management, consisting of guidelines for health care professionals on how to

convey the information, together with handouts for their patients (Maldonato, Segal, & Golay, 2001). The rationale behind this '5 minutes survival kit', it is explained, is that lack of time and lack of guidelines 'is, and always will be, a frequent excuse for not educating patients with diabetes' (www.desg.org). Concerning the issue of empowerment discussed above, the DESG wants to position itself in contrast to the more traditional paternalistic approach within diabetes care (Maldonato, Segal, & Golay, 2001), stating that its goal is 'to improve the quality of life of diabetes patients in Europe through the development and evaluation of educational programmes designed to foster independence for the patient [..]' (www.desg.org). When looking into the material, however, it seems very similar to the behaviour change interventions discussed above, as it also seems to be focused on barriers to adherence, while not explicitly addressing issues such as the communication between doctor and patient, or the 'three key consciousness raising experiences' as described above.

Of more advanced CAL systems are diabetes simulators being designed for use in diabetes school settings and during consultations, as well as in educating non-specialist health professionals, e.g., in primary care (Lehmann, 1997b). One of the earliest examples is DIABLOG developed by Biermann and Mehnert, which allows for modelling variability in insulin sensitivity (Lehmann & Deutsch, 1995). Another example is the 'Diabetes Simulator' by Albisser and colleagues, which allows for measuring the degree to which a patient conforms to the physician's instructions about regularity of meals, dietary content, and lifestyle, in terms of a single variable called 'compliance' (Lehmann & Deutsch, 1995). A third example is the AIDA system (Lehmann and colleagues), which is a widely distributed freeware web-based interactive educational diabetes simulator (Lehmann, 1994; Lehmann et al. 1994; Lehmann & Deutsch, 1995; Lehmann, 1997a-b, Lehmann, 2000; Tatti & Lehmann, 2003). Originally, AIDA was intended for diabetes specialists as a decision support system. But since it was not found accurate enough for individual patient glycaemic prediction or therapy planning, its purpose was redefined as an educational tool being equipped with a number of educational case scenarios. And while the 'Diabetes Simulator' arguably is instantiating an anti-empowerment approach, this may be contrasted by the pedagogical thinking behind AIDA as it is expressed by an old proverb:

> "If you give a man a fish, you give him a meal – if you teach a man to fish, you feed him for life." (Lehmann, 1997b)

The rationale is that the simulator can help in developing a deeper understanding of the dynamics of glycaemic control, and thus motivated patients should be in a better position to optimise their own therapy. But due to the lack of validation studies, Lehmann emphasizes that the goal of the

current AIDA system is not to function as an individual patient decision support system. However, Lehmann is welcoming a 'next generation' of validated simulators, being able to use SMBG for patient specific parameter estimation and to account for the 'Somogyi effect' (Lehmann, 1997b).

Lehmann lists a number of theoretical benefits of using current simulators in educating diabetes patients: Simulators 1) are fun to use as patients guided by their own curiosity, 2) provide accurate and immediate feedback, which is paramount in learning processes, 3) provide medium for demonstration of dynamics which are difficult to describe verbally, 4) forces users to reflect on discrepancies between SMBG and the behaviour of the simulator in order to reconsider factors, 5) help communication between patients and doctors, while patients 6) may end up as their own experts on the system, trained to identify problems and solutions (Lehmann, 1994). Documenting such educational benefits, however, remains a challenge (Lehmann, 1997b). A study by Bierman and Mehnert on the experiences of 22 Type 1 subjects using DIABLOG showed that one third of the patients found it confusing that the simulated data were sometimes different from their own blood glucose data (Lehmann, 1997b). A study by Hedbrant and colleagues on the experiences of 11 diabetic teenagers using a simulator called 'Sarimner', report that, even though the simulator-training was found enjoyable, a side-effect in some patients was an increased level of guilt and an alienation from medical professionals (Lehmann, 1997b). In addition, Lehmann reports on comments received by some established patients who found that the benefit of the AIDA system was only minor because of their own long-standing experience with diabetes (Lehmann, 1997b).

Furthermore, it has been hard to show clinical benefits of using simulators in diabetes education (Lahtela & Lamminen, 2002). Only recently, an initial proof-of-concept pilot study on the feasibility of a randomised, controlled trial (RCT) approach has shown a significant short-term clinical improvement in a smaller number of subjects (N = 22), in terms of a decrease in HbA_{1c} levels (from 7.2% to 6.4%, p=0.01) as well as in the number of 'hypos' (from 31 to 14, p=0.03) after lessons with AIDA (Tatti & Lehmann, 2003). In their discussion on these findings, however, Tatti & Lehmann point out that 'it may be one thing to show a short-term improvement in the HbA_{1c} level – but another to actually show a longer-term benefit or improvement in metabolic control'. Furthermore, the authors discuss a number of confounding factors, such as the influence of the teachers, and differences in the length of simulator-based and conventional lessons. What is more, it could be added that this study does not look into educational benefits in broader terms. Finally, to point out a list of confounding factors does not exhaust the debate on the methodological

difficulties of evaluating the educational potential of ICT systems within the RCT tradition. I will come back to this debate later.

Telemedicine and surveillance systems: Telephone, mail, or sms-based remote-care systems, including doctor-oriented digital screening systems, or 'visit-by-visit' systems consisting of data management systems and advisory tools to assist in (remotely) updating therapeutic protocol, and patient-oriented 'day-by-day' systems for the collection and transmission of home monitoring data and self-management actions as well as providing therapeutic advice.

At present there is little evidence that telemedicine can guarantee a better long-term outcome or reduce treatment expenses significantly (Lahtela, 2002). The potential, however, has been advocated since the early 1980s (Belazzi et al., 2002). The term 'telemedicine', of which the prefix derives from the Greek word 'tele' meaning 'at a distance', was coined in the 1970s to refer to health care delivery where physicians examine distant patients through the use of telecommunications technologies (www.advcomms.co.uk). The concept now refers to the use of telecommunication technologies to deliver medical information and services to locations at a distance from the caregiver or educator (www.fao.org), or even more broadly, to the transfer of electronic medical data (Brown, 1995). Earlier experiences of telemedicine in diabetes management in many cases only comprised the transmission of SMBG by modem-based equipment, and only in some cases patients would receive advice over the telephone on insulin adjustments and food intake upon transferring results to the clinical centre (Gomez et al., 2002). A recent review of ' the state of the art of telemedicine support for diabetes' lists three kinds of systems (cf. Belazzi et al., 2002):

- Telephone assistance, where patients periodically receive phone calls from a health care provider, who gives them advice about their therapy, and/ or educational information;
- visit-by-visit systems, devoted to assist physicians in interpreting home monitoring data in order to update therapeutic protocol;
- complete assistance systems, which integrate the visit-by-visit philosophy with the capability of providing day-by-day assistance to patients, i.e. the supply of therapeutic advice to patients during every day self-management of the disease.

It can be discussed, however, whether 'visit-by-visit' systems are telemedicine systems, as, for instance, decision support systems do not necessarily rely on the transfer of medical data, let alone, the distant communication between care provider and patient. And while the list seems to be focusing on the technical differences of telemedicine systems, it does not

explicitly indicate whether this includes SMBG monitoring systems, as mentioned by two other recent reviews (Gomez et al., 2002, and Lahtela et al., 2002).

To better suit the purposes of this review focusing on ICT systems to support active patient participation in IDDM care, I will suggest another way of categorising telemedicine systems. Instead of focusing on differences in terms of technology, I will focus on differences in types of interactivity mediated by the telemedicine systems. Here, I am inspired by a model presented by Jensen (1998) as a way of categorising types of interactivity, which is founded on two questions concerning power in all information traffic: who owns and controls the content of the information, and who controls the distribution of the information? In combination with two possible positions in the transmission of information, being the 'provider' and the 'consumer', this results in four principally different communication patterns:

Communication patterns	Information produced by a central provider	Information produced by the consumer
Distribution controlled by a central provider	**Transmission**	**Registration**
Distribution controlled by the consumer	**Consultation**	**Conversation**

Table 1.2: A typology of communication patterns (Jensen, 1998).

While this model was imported from mass communication research, Jensen's goal was to establish a framework to understand various forms of 'interactivity' as a new concept within media studies in order to analyse communication patterns mediated by the new (ICT-based) media. Thus, 'transmissional interactivity' can be exemplified by choosing between various conventional TV shows; 'consultational interactivity', by gathering information from a Web site; 'conversational interactivity', by an Internet-based discussion group; while 'registrational interactivity' can be exemplified by Web sites being taylorised by way of 'cookies'. (More elaborate versions of Jensen's model, e.g., distinguishing between synchronic and diachronic interactivity, are left out here for the sake of simplicity).

Since the question of active patient participation perpetuates the question of power, this model seems well suited for the purpose of analysing forms of interactivity within telemedicine. Nevertheless, while still being em-

bedded with some of the preconceptions of mass communication research, the model has to be adjusted when being imported to the field of telemedicine within diabetes care. Thus, I will argue, the focus on information ('who controls the distribution and production of information?') has to be altered. Firstly, telemedicine is not just a matter of information distribution, but has to do with the distribution of health care services. Hence, the two positions 'information provider' and 'information consumer' will be understood as 'health care provider' and 'patient', respectively. This may not by controversial. However, one needs to further reflect on how the terms in Jensen's model apply to telemedicine. Contrary to a very straightforward use of Jensen's model, I will refrain from including, e.g., simple broadcast media shows on medical issues into the concept of telemedicine in terms of 'transmission'. I will argue that health care services by principle has to rely on information coming from the 'consumer' in order for the distribution to be 'controlled'. – An incident of a child finding a glass of pills in a park and eating them will not be an instance of a health care service! Instead, it is a case of uncontrolled distribution of medicine. Corollary, any instance of health care services will be depending on information coming from the patient(s), from which the health professionals make the medical decisions. And thus, in any instance of telemedicine, both the patient and the health care provider will be providers of information. What is more, from a logical point of view, the information coming from the patient to the doctor is primary to the information coming from the doctor to the patient – and as discussed above, within diabetes care, the amount of information coming from the patient far exceeds the information coming from the doctor, while a major challenge is finding means to sustain the administration of home monitoring data. To sum up, in telemedicine within diabetes care, it is not only a question of distributing information from providers (doctors) to consumers of health care services (patients) – it will always be the case that both the provider and the consumer are producers of information, and what is more, supporting the flow of information coming from the patient is primary to supporting the feedback flow of information coming from the doctor.

Nevertheless, while drawing on Jensen's model of interactivity, and trying to retain as much of the core intend of the model as possible, I will, firstly, focus on the question: who controls the flow of information in health care delivery within IDDM care being mediated by telemedical technology? Next, concerning the vertical axis of the model having to do with the production of information, since the information coming from the patient is understood as primary, I will distinguish between systems meant for surveillance (i.e., monitoring patient data on a daily/ regular

basis), and non-surveillance systems mediating occasional support of the patient. Finally, concerning the horizontal axis of the model having to do with who controls the distribution of information, since the undercurrent theme of this review has to do with active patient participation, I will distinguish between systems approaching patients as 'passive recipients' or as 'active recipients' of remote diabetes care.

Following these principles of analysis, 'transmission' will be the case where the patient is merely a passive recipient of health care, while the doctor asserts control, e.g., in terms of initiating the communication, or in eliciting certain information from the patient, while not relying on daily home monitoring data. 'Registration' comprises ways in which health care professionals keep track of patient data on a daily basis, either diachronically, or synchronically. 'Consultation' concerns systems through which patients seek medical support without relying on the transmission of home monitoring data on a daily basis. And, finally, 'supervision' (as a more suitable alternative to the term 'conversation'), concerns systems by which health professionals are able to assist patients in their daily self-management of their disease when relying on home monitoring data.

On a final note concerning my use of this model, it may seem odd, for instance, that I include memory-meters and electronic transmission of home monitoring data in 'registrational systems': firstly, because patients undertaking the laborious task of measuring their blood sugar level on a regular basis are hardly to be considered 'inactive', as opposed to being 'active' patients; and secondly, because the patients can be said to control the flow of information, as they could decide to stop transmitting them at any time, or even stop measuring them. Admittedly, these problems disclose a vagueness of the model concerning what counts as 'active' or 'passive' reception of health care. Bearing in mind that this distinction is a core issue of the complicated matter of active patient participation as discussed above, I have chosen to leave it this way when presenting the model of telemedical interactivity. Hence, it is open to various views on this issue. However, the way I use this model reflects my sympathy for an understanding of 'active patient participation' and 'empowerment' being more than mere compliance. Furthermore, concerning the registration of home monitoring data (i.e., 'registrational interactivity'), what kind of data the patient registers and when he or she is supposed to register them is likely to be determined (i.e., controlled) by the health professionals by default.

The resulting overview of the forms of telemedicine systems found in the literature is as follows:

Telemedicine in IDDM care	**Non-Surveillance**	**Surveillance**
Patient as passive recipient	**Transmissional** tele-consultation (CAL) telephone assistance/ NTS Care*Results*SM (mail, Internet, IVR)	**Registrational** memory-meters (SMBG) modem transmission of home monitoring data ISF-based monitoring
Patient as active recipient	**Consultational** AIDA (web-based CAL) D-Net (discussion group)	**Supervisional** integrated day-by-day and visit-by-visit systems: ROMEO, LifeMasters, DIABTel, T-IDDM

Table 1..3: An overview of telemedical and surveillance systems found in the literature sample categorised according to a typology of telemedical interactivity.

Transmissional systems: including tele-consultation, telephone assistance, and telephone-based interactive voice response (IVR) systems. Few studies were found in the literature having transmission as its focal form of telemedical interactivity. Izquierdo and colleagues (2003) compared teleconferencing to in-person encounters between one patient and one health professional in order to determine whether diabetes education could be provided through telemedicine technology. Hence, it was used as a CAL system. The educational talks were provided in terms of a series of one-on-one conversations in both cases, and were focusing on bringing about self-care behaviour change in the patients through supervised goal-setting. The study found similar significant improvements in terms of metabolic control and stress reduction, while patient satisfaction was high in the telemedicine group. Another study in the sample (Howells et al., 2002) looked into the effects of educational talks via telephone. This study was focusing on the effects of providing (social) support in terms of non-directive 'Negotiated Telephone Support' (NTS) interventions, and therefore seems not to match well the pattern of transmissional telemedical interactivity. However, this depends on which level of communication one is addressing. As the study concludes, 'contact, independent of content, appears to be a key element' in facilitating behaviour changes in some patients. One can say the form of intervention in this study was transmitting basic social contact as a form of health care service in itself. (This study will be further discussed in the final section of this review concerning social support). An example of transmissional telemedicine, which is not a CAL system, is a disease management program, Care*Re-*

*sults*SM , employed by an American health maintenance organisation (HMO) in order to encourage its members' self-management and intervene in their care with only limited nurse interventions (Gomaa et al., 2001). A number of populations of HMO members (in total, 250.000) were targeted as sufferers from a chronic disease, and were asked to complete a survey being administered through various media (mail, Internet, and IVR services), to measure self-management issues, such as self-management knowledge, health risk, and compliance. The respondents (in total, 93.000) afterwards received an individually compiled 'Personal Health Guide' containing patient-specific information and goals based on his or her answers to survey questions, while the major goal was for the members to use the health plan as the foundation for discussions with their physicians. The intervention resulted in significant gross savings as well as a 55.2% increase of participants suffering from diabetes receiving an HbA_{1c} test.

Registrational systems: including memory-meters (SMBG), modem transmission of home monitoring data, electronic interstitial fluid (ISF) sensors. Again, very few studies focus on this form of telemedical interactivity. One longitudinal study was looking into the effect of diachronical surveillance by way of SMBG memory-meters compared to paper-based logbooks (Strowig & Raskin, 1998). This study found that in patients who had been using intensive insulin treatment for a longer period of time, the memory-meter provided a needed incentive to test blood glucose levels more often, but also that the effectiveness of the meter might rely on frequent follow-up and feedback. In addition, this study reports on similar studies showing that patients only using paper-based logbooks 'over report or add phantom values to blood glucose records by as much as 40%', and that the 'use of memory-meters has been associated with greater self-reported understanding of diabetes treatment, increased perceived importance of blood glucose testing, and improved quality of the interaction with the physician' (cf. Strowig & Raskin, 1998). Another study presents a recent way of providing synchronical surveillance by way of non-invasive ISF sensors, being under development as a new generation of monitoring technology, which continuously captures glucose levels without finger pricks (Rohrsheib et al., 2003). Furthermore, the prototype being described makes the measurements available over the Internet, determines direction and rate of change in glucose concentration by way of an algorithm, and alerts both patient and health professionals in case of divergence from pre-determined boundaries of glucose control. However, no findings were reported on the actual use of the system.

Consultational systems: including discussion groups, and online advisory tools not relying on daily home monitoring data. Once again, only a few

systems were found having 'consultation' as its focal form of telemedical interactivity. What is more, these systems are already discussed in another section of this review, as some CAL systems fit into this type, such as patient-oriented online advisory tools not relying on daily home monitoring data, e.g., 'AIDA', and discussion groups (even though these do not belong to this quadrant in terms of Jensen's original model).

Supervisional systems: integrated day-by-day and visit-by-visit systems. An early example of a day-by-day system is ROMEO (Meyerhoff et al., 1994), comprising a memory-based glucometer, which additionally allowed the input of insulin doses, food intake and exercise, as well as optic and acoustic reminders to the patient. To enhance this registrational system, it further included a computer application with data visualisation tools. However, no advice was provided by the system. And while it was not transmitting any data to health professionals, a major objective was to augment discussions between patients and health professionals on visits. The system thus supports surveillance in a diachronical form. Unfortunately, it proved difficult to motivate patients to use the system, and the authors speculate that surveillance is demotivating, being 'an intensive intervention into the patients' private life'.

A similar but more recent supervisional system supporting synchronical surveillance is LifeMasters, intended for HMO members diagnosed with various chronic illnesses (Selecky, 2001). The system allows web-based day-by-day monitoring for patients to receive nurse assistance via telephone. Furthermore, the system entails data management and decision support tools for the health centre as well as automated alert triage supporting SMBG surveillance. The decision support facilities are not intended for patients, but to support self-care learning the patient application is equipped with data visualisation tools to illustrate their progress.

Two more recent systems also supporting synchronical surveillance are DIABTel (Gomez et al., 1996; 2002) and T-IDDM (Riva et al., 1997; Belazzi et al., 2002). Both systems consist of a web-based patient unit (PU) allowing day-by-day telemonitoring of patient blood glucose data and self-management actions, and a medical unit (MU) supporting telecare services between visits. This telecare is both in terms of synchronic surveillance (the doctor giving feedback to the patients), and consultational interactivity (the patient asking the doctor for advice via asynchronous messages). The goals of the two systems are expressed in ways, which sound empowerment oriented, however, with a slant of a medico-centric focus on compliance: DIABTel is intended to support 'supervised autonomy', which 'increases patients' independence and ability to make their own decisions without decreasing the necessary continual support and specialist supervision', whereas T-IDDM is intended 'to allow the patient

to customize the insulin therapy within the bounds established by the physicians.' Interestingly, whereas the MU's in both systems entail tools for data analysis and decision support, the PU's do not. Two recent 'feasibility pilot studies' about the systems (Gomez et al., 2002; Belazzi et al., 2002) both show a trend towards improved clinical outcomes, while both systems proved feasible in performing a tighter control of the patients' metabolic situation. Furthermore, while the use of T-IDDM led to 'indications of improved communication' and 'a closer contact between patient and physician', patients using DIABTel showed 'a very limited use of the possibility of an electronic communication with doctors', while physicians using this system performed more therapeutic changes during DIABTel period than in the control period. However, despite the statements concerning the motivation of these supervisional systems, none of the two studies look into the question concerning patient participation or empowerment.

Social support systems: including Internet-based or Web-based discussion groups, both non-moderated and moderated by diabetes specialists, providing social and emotional support for patients and their relatives.

Interestingly, social support systems are seldom mentioned in reviews on the application of computers in diabetes care (Lehmann, 1994; Lehmann & Deutsch, 1995; Lehmann, 1997a; Balas et al, 1998; Belazzi et al., 2002; Belazzi, 2003), while Lahtela & Lamminen (2002) mention discussion groups among systems for 'diabetes education'. However, although not entirely consistent, most studies have reported significant relationships between social support and health (Glasgow et al., 1999; Zrebiec & Jacobson, 2001). Research indicates that to bring about patient lifestyle changes ongoing support is required (McKay, 2002). It has also been speculated whether the high level of success and retention in the DCCT was partly due to the intensive level of ongoing patient contacts and social support from the health professionals, as the patients in the intervention group received on average 32, 20-min diabetes-related telephone calls per year, in addition to two educational calls per year and ad hoc 'trouble shooting' calls (McKay, 2002; Howells et al., 2002). One randomised controlled trial studying this effect in 91 adolescent Type 1 patients did not, however, show a significant benefit in terms of glycaemic control by means of a non-directive Negotiated Telephone Support intervention, while keeping a 'conventional' insulin therapy using twice-daily regimens (Howells et al., 2002). Nevertheless, the study concludes that:

> It seems that structured but basic counseling about general life problems from a member of the diabetes team appears to help young people feel able to overcome the barriers to their diabetes self-care. Contact, independent of content, appears to be a key element. The

> study suggests that to improve glycaemic control the two elements, living with diabetes and intensive insulin therapy, need to be considered as equal objectives. (Howells et al., 2002)

It has thus been studied whether ICT systems could be employed to provide social support in a more feasible way than the amount of support provided by the health professionals within DCCT.

During a 21-month longitudinal study, Zrebiec and Jacobson (2001) has evaluated the feasibility and usefulness of a two professionally moderated web-based discussion groups (named 'Get motivated' and 'Family affairs') being open for patients with diabetes and their family members. While the discussion groups attracted a lot of users (in total, 47365 users from 59 different countries), it was found that only a minority of the users (about 10%) were actively taking part in the discussions, the rest of the users being mere 'lukers'. Nevertheless, most respondents (79% of 569 completed satisfaction surveys) found that the chat rooms helped them cope more positively with their diabetes. Also, while most of the posted messages addressed nutrition (42%), the emotional impact of diabetes came in second (18%). Partly in support of this finding, an earlier study comparing the use of two listservs, one on diabetes type 1 and one on an acute disease, has shown that while the latter was primarily facilitating emotional support, the more established users of the diabetes listserv primarily shared information on practical issues (Schoch & White, 1997).

Also, in a number of studies focusing on behavioural interventions, Glasgow, McKay, and colleagues (McKay et al., 1998; Glasgow et al., 1999a -b; McKay et al., 2002) have been looking into the potential benefits of an Internet-based support system, D-Net. In an initial study on the feasibility of Internet support in 111 Type 1 and 2 adult users of the D-Net website, showed that it was perceived helpful and that the social support group was the most popular facility (McKay et al., 1998). In addition, it was considered 'feasible' and cost-effective to maintain, while self-management outcomes were not evaluated. In a later study, 221 users responded to an online survey showing that those participants who logged onto D-Net the most also reported the most support on the Diabetes Support Scale (Glasgow et al., 1999a). However, in a final study in 160 Type 2 patients, peer support did not produce significant short-term behavioural effects, and only very slight improvements in quality of life, while an online personal coach intervention both proved 'feasible' and produced 'encouraging effects' on dietary behaviour change (McKay et al., 2002). This study concludes that similar programs might want to more actively prompt or 'seed' group discussions.

Summing up on current literature on ICT systems in IDDM care, in the face of a call for systems supporting active patient-participation, the doctor-oriented approach seems to prevail in all five categories of systems:

- Data management/ EMR systems are primarily doctor-oriented, since, generally, patients are not typically counted among the primary users of EMR systems. Hence, patient-oriented consumer health records to support self-directed disease management are rare.
- Decision support systems are mostly doctor-oriented, while the most advanced systems for patient use are only designed for the simplest cases of insulin adjustment.
- CAL systems: Many such systems are designed for targeted behaviour changes, i.e., being compliance-based, while Lehmann's writings on AIDA may provide an alternative to this thinking.
- Telemedical systems: Concerning telemedical systems, surprisingly, one of the most empowerment-oriented systems mentioned were a low-technology transmissional system (based on 'non-directional telephone support'). Complementary to this type of telemedical interactivity, two supervisional systems (DIABTel and T-IDDM) are intended to support 'supervised autonomy' and 'patient independence', however, a) within limits set by the health professionals, b) while reserving decision support tools for the health professionals, and c) without monitoring patient participation and development in the feasibility studies.
- Support systems: The mere existence of such systems indicates an acknowledgement of the importance of supplementing the traditional focus on metabolic control. However, a first observation concerns the absence of such systems in many reviews. Next, the major part of the research on support groups stem from CAL research being focused on targeted behaviour changes in patients, the benefits of which are measured primarily in terms of improved metabolic control or compliance.

This trend also shows in a recent review listing 49 ICT systems in diabetes care, only a dozen of which are intended for patient use (Gorman et al., 2000).

1.2.1 DiasNet

Since the early 1990'ies, the prototype 'DiasNet' has been developed at the Aalborg University by Hejlesen and colleagues, partly in collaboration with clinicians at The Royal Bournemouth Hospital, UK (Hejlesen et

al. 1997, 1998, 2000; Cavan et al., 2001, 2003; Plougmann et al., 2001, 2003). Originally, DiasNet was built as an advisory system, called 'DIAS', designed to assist insulin dose adjustment in type 1 diabetes. Specifically, DIAS was aimed to detect problems in insulin absorption or kinetics and identify reasons for hypoglycaemia or hyperglycaemia. DIAS builds on a model of the human carbohydrate metabolism being implemented in a causal probabilistic network (CPN or Bayesian network) and has been evaluated in several controlled clinical studies, which have verified the ability of the model to accurately predict blood glucose, while also suggesting a significant effect of using the system.

The system is operated in two modes: the learning mode and the prediction mode. In the learning mode, patient data on SMBG, insulin injections, and carbohydrate intake from one or more days are used to estimate patient specific parameters, i.e., the system is adjusted to fit to each individual patient. Here, the system can be used in estimating a patient's insulin sensitivity (IS). In the prediction mode, the estimated parameters are used to make predictions of the blood glucose concentration. On the basis of data on insulin dose, carbohydrate intake and blood glucose concentration, the system is able to predict hourly blood glucose concentrations as an effect of suggested changes in the insulin regimen or meals on the blood glucose concentration. Also, the system can select insulin regimens, which are optimal accordingly to the mathematical model. Furthermore, and importantly, the system can help in taking account of a tendency to overcompensate low blood glucose levels by the Somogyi effect by visually comparing the simulation with the actual SMBG curve (see Figure1.1, next page).

DIAS may thus qualify as what Lehmann called 'the next generation' of diabetes decision support systems a) being based on a validated model, b) using the patients' own data for parameter estimation, and c) making it possible to take account of the Somogyi effect (cf. Lehmann, 1997b).

Furthermore, in combination with the use as a decision support system for clinicians, DIAS has also been employed as a learning tool for patients. The system has thus been integrated into the patient education during diabetes school sessions at The Royal Bournemouth Hospital, UK. An essential part of education of diabetes patients is learning how to achieve good glycaemic control. Like with AIDA, compared with traditional educational material, what make it useful as a teaching tool are its dynamic representations of the effects of insulin injections to show the effects of variations in, e.g., the insulin dose, carbohydrate intake, and the timing of insulin injections. Using the system, patients can experiment with adjustments of insulin doses or meal sizes, and thereby learning how to cope with various situations. In this way different therapeutic and dietary

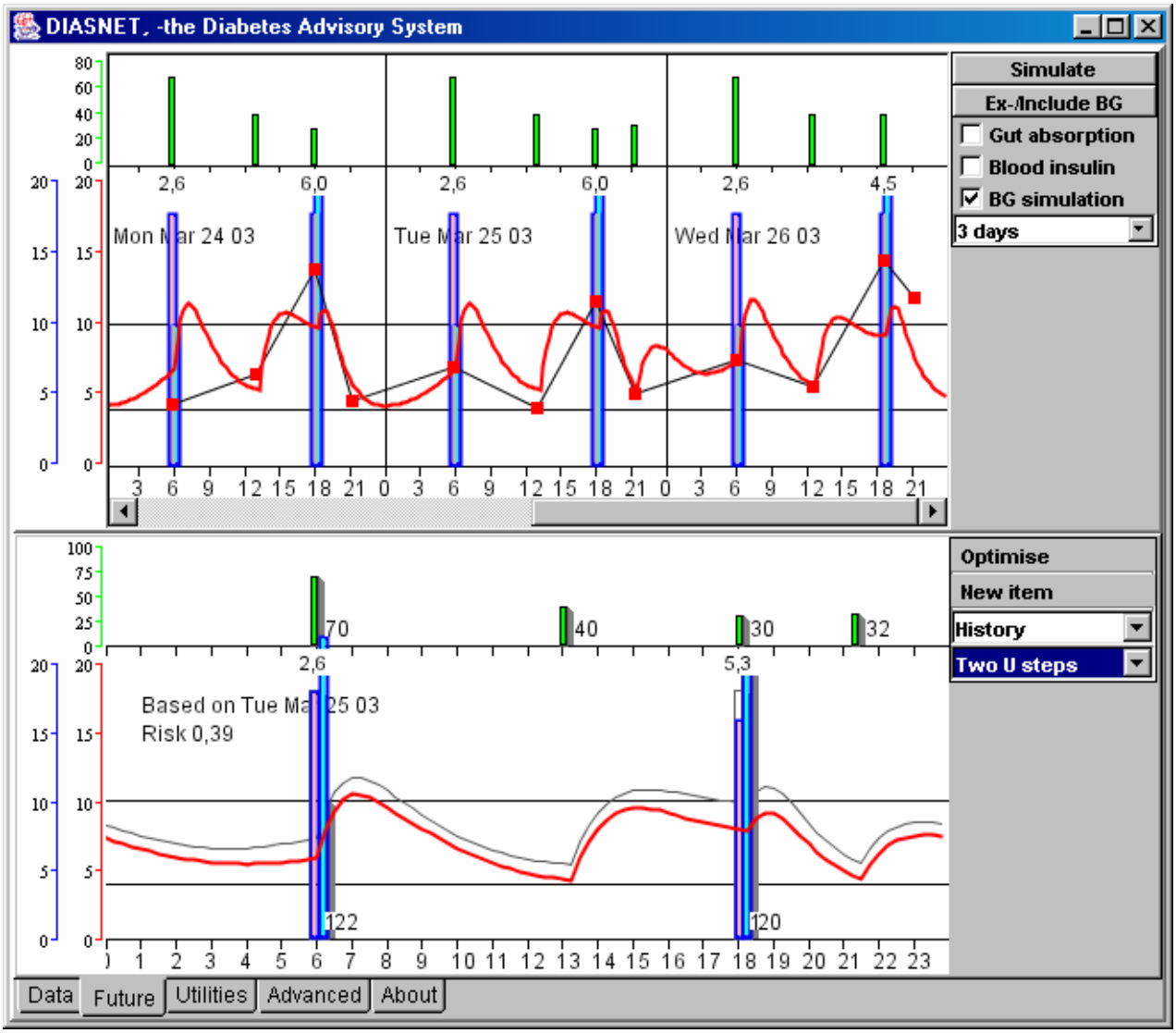

Fig. 1.1: The DiasNet interface. The upper half shows three days of data as entered by the patient on carbohydrate content in meals (upper green bars), regular and NHP insulin injections (lower violet and blue bars), and blood glucose measurements (red squares connected by straight lines in black). The recommended range of blood glucose between four and ten mmol/l is indicated by horizontal lines. The smooth red curve shows the blood glucose prediction generated by the system. The lower half of the figure shows one of the focal facilities of DiasNet being a dialogue (to be named 'the Future dialogue' in this report), which allows the patient to focus on a single day experimenting with changes of meals or insulin doses by simply using the mouse to drag the bars, and immediately seeing the resulting blood glucose prediction. Or, alternatively, to generate an optimisation, and seeing the system's advise in terms of insulin adjustments, as shown in the above example. The lower grey and red curves show the blood glucose predictions before and after the adjustments, respectively.

alternatives can be tried out, allowing the patient to gain experience in achieving glycaemic control, without the risk of actually experiencing hypoglycaemic or hyperglycaemic (inappropriately high blood glucose) episodes. In addition, compared with a similar system like AIDA, one of the major benefits of the system is that it uses the patient's own data.

Many patients showed a striking enthusiasm seeing their data being used to generate their own personal advice (Hejlesen et al., 2000). Also, the system can help in improving the dialogue between the patient and health professionals during visits or in a diabetes school setting concerning patterns of SMBG variations or to identify possible episodes of nocturnal hypoglycaemia.

Finally, as a third stage, the prototype has been developed into a web-based application, now called 'DiasNet', to be accessible from the clinician's office PC as well as from the patient's home PC using a standard web browser. The scope of this version of the system has thus been shifted to also being a tool for the patients. This way, the patient can sit at home entering his data into the system running on his home PC, while the clinician can use a web browser on his office PC to view data that the patient just entered. Thus, DiasNet can be used as a consultational system, as the patient can experiment with their own data, adjusting insulin doses or meals sizes, and thereby learning how to cope with various situations. Furthermore, since the health professionals can access the data entered by the patients, this will allow patients to be regularly monitored remotely, and as a routine part of the ambulatory visits, clinicians can use DiasNet to get a clear overview of the patient's data without having to spend time deciphering a hand written patient diary. DiasNet can thus be used both as a registrational and supervisional system, depending on the degree to which the patient is actively taking part in the disease management. In the first case, the health professionals can contact the patient to discuss a problem and to suggest alterations of a regime, while in the second case the patients can contact the health professionals to discuss their concerns by referring to their current data (Hejlesen et al., 2000).

A study following the Diabetes Project in Frederikshavn for half a year looking into the effects on three patients as well as the diabetes team showed promising results (Dinesen et al., 2003). The patients experienced a) enhanced security and contact with the clinicians due to surveillance; b) enhanced control over their diabetes; c) decrease in insulin doses and weight loss; d) enhanced awareness about disease management issues, such as the importance of counting carbohydrates, doing exercise, as well as taking account of the counter-regulation effect; e) decreased importance of having control visits every three months. As for the experiences of the diabetes team, the health professionals reported 1) enhanced competence of the nurses to regulate insulin regime; 2) improved communication with the patients and closer control; 3) enhanced awareness of the Somogyi effect; 4) enhanced interest in teaching carbohydrate counting; 5) improved visibility of the patients' SMBG profiles; 6) enhanced feeling of being a team; 7) while also experiencing difficulties in adjusting to

new ways of working, e.g., communicating with the patients virtually, or merely to take time away from other routines to sit down by the screen. A similar six-month study with six patients in Bournemouth, however, revealed that while the patients found the system helpful and that well motivated patients can collect data and enter them into DiasNet to aid self-management of their diabetes, difficulties with data entry hindered its use (Cavan et al., 2003).

These three stages in development of the system and the uses of it nicely illustrate a development from a traditional medico-centric approach toward a more patient-centric approach. DiasNet is a result of an aspiration to integrate those views. As stated by the developers,'[t]he Internet based tool [..] is developed under the assumption that a decision support system in the classical sense may not be enough – that more emphasis should be put on patient empowerment, and that the keywords are *education* and *communication*' (Hejlesen et al., 2000).

To sum up on this characterisation of DiasNet, as a system it may qualify as what Lehmann called 'the next generation' of diabetes decision support systems, while at the same time its development has advanced to integrate a range of other uses, both as a CAL system as well as a telemedicine system potentially supporting registrational, consultational, and supervisional interactivity, as various ways to support patient empowerment.

1.3 The question of evaluation

1.3.1 An obstacle for computerization

Even though existing ICT systems may provide a possible answer to some of the challenges of diabetes disease management, most systems have faced limited dissemination, while few are under development at the present time (Belazzi, 2003). Focusing on decision support systems, such as DiasNet, none of the numerous systems developed during the last two decades have, up till now, gained widespread use or acceptance (Bott et al., 2000).

One type of reasons for this apparent lack of success might have to do with the validity of the system model in terms of problems in handling the interpatient and intrapatient variability, uncertainties in the data involved, and the fact that the blood glucose control in diabetes is influenced by numerous factors like stress, fever, exercise etc. Related to this, there is a problem of justifying reasoning in the computer-generated therapy adjustment suggestions (Lehmann, 1994). Another type of reasons is that even though the system model is validated, there is a lack of usefulness due to functionality problems, in particular a need for intuitive

graphical user interfaces, and what is more, most systems have been too difficult to use (Lehmann, 1994). A third type of problem has to do with computer 'fear' within health care regarding the considered impact of a system: The systems and their implementation may be seen as merely adding more to the professionals daily workload, or to the burden of IDDM for the patients (Gomez et al., 2002). Or the physicians might consider the decision support systems (either before or after they have been implemented) as detrimental to developing the doctor-patient relationship, as undermining their professional status or the art of medical practice, interfering with their professional autonomy (Lehmann, 1994; Kaplan, 2001). This points to a fourth type of problems being trouble with implementation and diffusion of a new system because of developmental constraints on the organisation in which the system is implemented, as well as lack of integration into other hospital IT systems (Belazzi, 2003). Also related to this question, a fifth type of reasons might be that systems have not been designed and put to use with an adequate purpose. As shown by Bijker, new technology needs time to maturate, that is, time for the technological frame to emerge; a technological frame structures the interactions among the actors around an artefact in terms of, e.g., the emergence of adequate problems for the emerging solutions (Bijker, 1995).

Finally, a sixth type of problems is associated with the evaluation methods (Kaplan, 2001; Wyatt & Spiegelhalter, 1990; Wyatt et al., 1994; Kristensen & Nøhr, 2001). In a recent review, it is argued that this problem mainly stems from the inadequacy of RCT (randomised controlled trials), which is a common research design within medical science and, unfortunately, also common when evaluating decision support systems (Kaplan, 2001). Some of the main reasons stated are that users' opinions make a difference, that it is difficult to determine the relevant variables beforehand, and that the assessment activities are having (and in effect, should have) influence on the systems development.

To tackle one of the essential problems in developing and implementing a system like DiasNet, I will focus on its evaluation. Existing evaluations of DiasNet and earlier versions of this prototype have mainly focused on its use as a medico-centric decision support system in order to find ways of refining the model. More work therefore needs to be done looking into DiasNet's potential contribution to meeting the challenges of patient participation in IDDM disease management.

1.3.2 Lack of research on how to assess systems like DiasNet

Looking for literature on how to evaluate DiasNet as a disease management system for patient-use, it soon appears that there is a scarcity of re-

search on how to evaluate such systems (Kaufman et al., 2003). This, in spite of the much-acknowledged importance of evaluating ICT systems and their impact on health care (Lehmann, 1997b).

To illustrate this problem, a literature search was conducted in MEDLINE/ PubMed (updated September 19th 2006) using the following search expression: ("Disease Management" OR "Managed Care Programs" OR "Patient Care Planning" OR "Self Care" OR "Models, Nursing" OR "Nursing Research" OR "Holistic Nursing" OR "Chronic Disease" OR "Preventive Medicine") AND ("Therapy, Computer-Assisted" OR "Decision Making, Computer-Assisted" OR "Computer-Assisted Instruction" OR "Internet" OR "Telemedicine" OR "Decision Support Systems, Clinical" OR "Communications Media" OR "Medical Informatics" OR "Ambulatory Care Information Systems") AND ("Assessment, Biomedical Technology" OR "Assessments, Biomedical Technology" OR "Biomedical Technology Assessments" OR "Technology Assessments, Biomedical" OR "Biomedical Technology Assessment" OR "Technology Assessment" OR "Assessment, Technology" OR "Assessments, Technology" OR "Technology Assessments"). This query was thus consisting of three parts, addressing the issues of disease management, computerisation, and assessment. The first two parts of the expression were taken from the literature review already reported on above, while the third part was consisting of all MeSH terms concerning technology assessment. The search was thus leaving out the issue of diabetes to make it less narrow. Nevertheless, the result was extremely meagre. While the first part of the expression (MeSH terms concerning disease management) lead to 259729 hits, and the second part (concerning the use of computer-based technology) gave 50530 hits, their combination with the third part (about technology assessment) resulted in no more than 22 hits. Furthermore, among these studies only 11 were found eligible, i.e. directly addressing the issue of computerised patient-oriented disease management. However, most of these 11 studies, the majority of them being reviews, only address considerations of the future potentials and challenges of integrating the emerging computer-based technologies into health care practice, especially telemedicine and surveillance technologies (Simpson, 2005; Bolz et. al., 2005; Kaiser, 2004; Frantz, 2004; Stefanov et al., 2004; Gomez & Clark, 2001; Hersh et al., 2001; Houston & Ehrenberger, 2001; Stoeckle & Lorch, 1997), while also 'the next great age' of nanotechnologies is addressed (Bathrick et al., 2002).

As it finally turned out, only a single study was identified by this search in MEDLINE/ PubMed directly addressing the issue of assessment methods regarding computerised disease management. In this article, Kaufman, Patel and colleagues (Kaufman et al., 2003) describe their use of us-

ability methods to facilitate the process of designing and re-designing a home-based telemedicine system, IDEATel, being mentioned above as a supervisional system, which similarly to DiasNet is intended to support supervised autonomy and patient independence. The authors describe their method as a 'multi-faceted approach to usability evaluation' incorporating two elements: cognitive walkthroughs of the system, and field usability testing of representational users in their homes. The latter is carried out by way of a video-analytic approach to provide an in-depth characterisation of the target population. Furthermore, the study focuses on (25) elderly diabetes patients and their limitations, taking account of age related decline of cognitive and psychomotor abilities. Hence, this study can be described as a 'classic' usability approach in the way that it is focusing on a system and its users, i.e., focusing on problems due to the limitations of the system's facilities and interface, and the particular abilities and limitation of its target users (cf. Nielsen, 1993; Molich, 2000; Kuniavsky, 2003, Ch.10).

Even though this study focuses on elderly patients, it might well provide a methodology for a similar study assessing DiasNet. However, as will be clear in chapter 2 it was not possible to intervene this intensely during the Diabetes Project to carry out a field usability test. Also, a heuristic inspection of DiasNet (i.e., a cognitive walkthrough) had already been carried out by other researchers (Kjeldskov et al., 2002). What is more, due to reflections on the challenges of evaluating disease management systems for patient-use I was planning to transcend (or supplement) the approach of a 'classic' usability study focusing on the system and its users. Without intending to make a sweeping critique of state of the art usability methods, something that far exceeds the scope of this study, I present these reflections in what follows.

1.3.3 Evaluation: Usefulness, usability – and copability

Evaluation can be described as acts related to measurement of exploration of a system's properties or quality characteristics related to a specific context (cf. Ammenwerth et al., 2004; Brender, 2006). As described by (Ammenwerth et al., 2004):

> Evaluation is the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation) the result of which informs a decision to be made concerning that system in a specific context (Ammenwerth et al., 2004).

Concerning the specific context of exploring the quality characteristics of DiasNet, as stated, I will focus on its usefulness as a diabetes disease management system for patient use.

As for disease management and prevention systems on the Internet, there are currently no existing guidelines specifically to evaluate health behaviour change programs (Cummins et al., 2003). As a strategy for evaluating knowledge based systems, Engelbrecht et al. differentiates between four levels of analysis: Verification, validation, human factors assessment, and clinical assessment (Engelbrecht et al., 1995), stating that human factors assessment seeks to determine whether or not a system is 'useful' and 'usable'. However, when reflecting on these concepts in relation to systems supporting disease management, I will argue that an assessment of human factors is closely related to clinical assessment.

Concerning the concept of clinical assessment, treatment outcomes in IDDM patients are often measured by metabolic variables, where glycosylated haemoglobin (HbA_{1c}) and the number of hypoglycaemia is the most common. An old systematic review of controlled clinical trials in computerized diabetes management identified 15 articles (all published before 1994) representing a total of 48 health outcomes measures, of which 40 measured health status, while only three measured social functioning, and five measured satisfaction (Balas et al., 1998). However, as observed in this review:

> As patient-centered medicine is advocated for all areas of health care, the role of technology also needs to be re-evaluated. Correspondingly, computers and their evaluations have to be responsive to patients' wants, needs, and preferences. (Balas et al., 1998)

Concurrently, I claim that the traditional focus on metabolic parameters needs to be complemented by other criteria of quality of care, which are relevant in the given context of diabetes disease management. Thus, we need to take account of the challenge of diabetes disease management and patient participation, as well as criteria for quality of care within this approach.

Concerning the concept of usefulness, a highly influential researcher within the field of HCI and user-centred design, Jakob Nielsen, presented a taxonomy on aspects of system acceptability, which includes the concept of 'usefulness'. In his taxonomy, 'usefulness', being a subcategory of *practical acceptability*, has two subcategories, *usability* and *utility*. Whereas utility has to do with the match between system functionality and user needs, usability has to do with how easy it is to make use of this functionality. Nielsen's list of usability aspects in this taxonomy includes *subjective user satisfaction, efficient to use, easy to learn, easy to remember,* and *few errors* (Nielsen, 1993). I here want to point out that utility and usability aspects are heavily interrelated in the individual use context, and that you cannot have a thorough usability analysis without a utility analysis. The user-interface of a modern two-seat sports car can be almost

identical to that of an economic station wagon. Thus, an analysis of the usability behind the wheel of the two cars could easily be very similar. But in everyday use, aspects like 'efficiency of use' or 'user satisfaction' might still be very different for the two cars as they match different life styles. In other words, even though we start out to focus on 'usability' of a system, eventually we will have to ask the broader question: 'What is the usefulness of this system?' I further argue that even though a tool has a high level of usability and utility, we still would not be sure whether the user would experience great usefulness in terms of enhanced ability to 'cope'. One example is the word processor: Some have argued that exactly because it has great functionality that is easy to use, it easily impairs the writing process as the user will be inclined to constantly edit the text or to reuse old material that site tracks the line of argument (Kock, 1995). Another example is the 'C-pen', which makes it possible to scan specific lines from a book and save those on a PC. The C-Pen saves the user from the workload of typing the citations. But even though the C-pen would have both the desired utility and be easy to use, it might just be too easy to end up with a fragmented book – instead of a note, which is easy to overlook. Thus, the C-pen has to be administered wisely in order to have great usefulness. As a third example, Beuscart-Zéphir and colleagues recently evaluated a computerized medical record specific for the anaesthetic consultation, 'Tabellar', stressing the point that the way information is represented may influence the cognitive processes relying on this information (Beuscart-Zéphir et al., 2001).

> The applications that are intended to handle medical data are closely intertwined with the physician's medical activity. This close physician–machine cooperation involves complex cognitive processes: the medical and anesthetic expertise of physicians is deeply involved in dialog with the interface. Under those circumstances, standard usability methods, such as heuristic evaluation or cognitive walkthrough [...], do not allow the identification of the major cognitive problems the physicians will encounter when dealing with the interface. (Beuscart-Zéphir et al., 2001)

Thus, their study showed important differences between expert and novice anaesthesiologists in the way they gather and record relevant information. Unfortunately, it also showed that Tabellar primarily was supporting the novice anaesthesiologists in a stepwise information gathering process while interviewing the patients, while putting inadequate restrictions on the workflow of the expert anaesthesiologists, who would sometimes deviate from a standard procedure by constantly taking account of an overview of the currently available information. This study thus emphasises the importance of taking account of the dynamic interplay between man and machine, the user being focused on his or her work, not the system.

And while the study merely suggests a refinement and expansion of 'standard usability methods', instead of transcending them altogether, I take it as a third example that a thorough analysis of usability will lead to a more complex question concerning the usefulness of a system, and that important aspects might be missing out from analyses focusing only on traditional usability aspects (as defined above).

To emphasise the importance of such aspects I therefore suggest a third concept in addition to usability and utility, namely copability – that a system should help the user to 'cope' with his or her focal challenge. I will argue that in order to make a thorough usability analysis of a disease management system like DiasNet it is important to approach the patient not merely as a user of a system, but as a person with a disease. I therefore suggest evaluating its usefulness in terms of how the system enhances a person's ability to 'cope' as a patient. To be more precise, I will describe how the system is integrated into how the patient is dealing with the disease as a part of everyday life. This change of focus is what a 'copability' analysis of disease management systems is about, neither having the system or the patient as its focal object, but studying how the system is mediating the patient's (own) object.

Hence, concerning the concept of 'usefulness' of disease management systems, I argue that an assessment of human factors will have to take account of the challenges of this approach. The system should help patients in coping with their disease. What is more, I argue that this question is closely related to clinical assessment, however, in a way that is exceeding the traditional criteria for quality of care in diabetes.

Hence, I will report from an explorative study on how to describe the usefulness of DiasNet as an IDDM disease management system in terms of how it is integrated into dealing with the disease as a part of everyday life, in terms of adoption and empowerment. The study includes both the development of the description method, as well as an evaluation of DiasNet, accordingly. While leaving out the issue concerning the medical benefits in a more narrow, or 'classical', sense, i.e., by reference to traditional health measures, I will discuss the integration of DiasNet into the patients' disease management in terms of 'adoption', and the benefits of this integration will be evaluated in terms of 'patient empowerment'.

2 Methodological considerations

This chapter intends to give a detailed account of the process and the contextual conditions of the CID project, Copability in Disease Management, in order to provide as much insight into the development of the qualitative and explorative study as possible.

2.1 The DDN Project and monitoring research

Describing the contextual conditions of the research project to be reported on in this work is like describing a Chinese box of projects. The over-all context was the DDN (Digital North Denmark) project 2000 – 2003, being a major project funded by more than DKK 650 mill. in total and consisting of 90 sub-projects (Møller, K. et al., 2002). It was initiated by the government to establish a regional 'IT lighthouse' to generate visions and experiences concerning an imminent 'network society'. The objective reads as follows:

> "The aim is to promote the development and use of IT – and through concrete projects to explore the prospects of the network society. The concrete projects are intended to support the electronic infrastructure, competencies development, e-commerce, the effectiveness and service of the public sector, the democratic dialogue as well as the opportunities of the individual citizen to exploit the potentials of the network society" (cf. Dirckinck-Holmfeld, L., 2004, p.34; my translation, eb).

As a part of the project a group of researchers was established at Aalborg University to monitor the DDN project. Concerning the over-all method of this research, the head of the group, Lone Dirckinck-Holmfeld, has indicated two fundamental issues. Firstly, to approach the concrete projects as social experiments with new technology to initiate 'learning in the region'. Concerning this issue, there are two sides of the coin: it is not only a question of developing and introducing new technology, but also a question of initiating a social learning process about how to make use of this new technology – which, in turn, gives feedback to the technological aspect of the process.

> Following the approach of the 'social experiments' it is not only the technological development in itself, which is interesting, but the technology as integrated in, supporting, mediating a negotiated and adjusted praxis, being the main concern of the experiment (Dirckinck-Holmfeld, L., 2004, p.40; my translation, eb).

Dirckinck-Holmfeld thus emphasises that the DDN project is to be assessed in terms of whether or not it has generated social learning proc-

esses. Thus, the focal aim of the monitoring research should be to disclose and conceptualise the experiences from the complex processes of learning and conversion being initiated by DDN. Hence, she characterises this kind of research as a hybrid between ground research and evaluation. Secondly, she points out three ways of positioning oneself as a researcher undertaking such research:

- 'Sideline research', where the researchers analyse, assess and generalise the initiated experiences in relation to the overall objective of DDN without any direct involvement in the concrete projects;
- 'dialogue research', where the researchers provide advisory observations concerning the development of a given project, while also conceptualising and generalising the experiences and results of the project;
- 'action research', where the researchers are actively taking part in a given project, directly contributing to the development and implementation of the new technology (cf. Dirckinck-Holmfeld, L., 2004, p.41).

The monitoring research was divided into a number of segments of DDN projects to be monitored, in which the current project to be reported on here was allocated the segment of 'Competencies and education', which was concerned with ICT projects supporting education, labour market, culture and recreation, as well as welfare and health care. The current research project was concentrating on the latter.

2.2 The Diabetes Project in Frederikshavn

Concerning ICT in health care, the largest project was 'The Digital Hospital' (in Danish, Det Digitale Sygehus, DDS) October 1st 2001 through December 31st 2003 with a budget of over DKK 36 mill. This was a highly ambitious project itself consisting of 13 sub-projects concerning the implementation of a number of various ICT systems at several departments of the hospital in Frederikshavn, including the Diabetes Project at the Department of Internal Medicine. The overall goal of the DDS project was to increase the citizens' satisfaction concerning the secondary health care sector via the integration of ICT systems to ensure an improved and more continuous treatment of patients throughout their contact with the health care system, as well as to provide more openness towards the patients and to support the patients in a new and more active role as competent patients by giving access to data on their own treatment (Christensen, 2001). Furthermore, an essential aspect of the project plan was to generate knowledge about how to combat organisational barriers toward the implementation of ICT within a hospital setting (Christensen,

2001). Hence, this ambition nicely suits the above-mentioned concept of 'social experiments with technology' having to do with the organisational aspects of implementing ICT[3]. The Diabetes Project was only a minor part of the DDS project. However, among the 13 DDS projects in total, the Diabetes Project was one of the only projects directly involving the citizen, i.e. the patient, in exploring new prospects of ICT based communication. The Diabetes Project was scheduled July 1st 2002 through July 1st 2003 with the aim of developing ICT based methods directed at patients suffering from diabetes and other serious chronic diseases to enhance their participation into their own treatment as well as their understanding of the disease, and thereby to ensure a more effective treatment of the disease and its consequences (Christensen, 2001). More specifically, the goal was to carry out a feasibility study to generate experiences of integrating DiasNet into the treatment of a smaller number of outpatients with Type 1 diabetes, including a diabetes school program and control visits.

As mentioned earlier, previous prototypes of DiasNet had already been integrated into diabetes school programmes in Bournemouth. Thus, half a year before the take off of the Diabetes Project in Frederikshavn, in summer 2002 the diabetes team from Frederikshavn, accompanied by Ole K. Hejlesen and colleagues, visited The Royal Bournemouth Hospital. The aim was to study the integration of DiasNet into a diabetes school practice, in which DiasNet was used both as a decision support system and as a CAL system (i.e., as the DIAS system) as a part of the discussions between the health professionals and the patients. At that time, however, it was still not implemented as a telemedical system (i.e., as the web-based DiasNet system). The Bournemouth diabetes school model is originally inspired by the work at the Department of Nutrition and Metabolic Diseases at the Heinrich-Heine-University in Düsseldorf (Bott et al., 2000). But whereas the diabetes school in Düsseldorf takes place every day within a full week, the outpatients in Bournemouth only attend the diabetes school half a day every week for a month. This way it is possible to work with the patients' experiences when trying to integrate what they are learning in their own daily practice (Cavan et al., 2003).

In Frederikshavn, the diabetes school strategy, which was defined in collaboration with Hejlesen, was to augment the diabetes school model from Bournemouth with two elements. Firstly, by introducing the patients to DiasNet as first-hand users themselves, and secondly, by a following six months of weekly correspondence between the patients and the hospital

[3] Some of the experiences of these and other DDN projects concerning ICT implementation within health care are described in (Boisen & Bygholm, 2004).

via DiasNet. To provide access to the system, Ole K. Hejlesen devised a web site[4], by which patients could access DiasNet with a personal password, enter their data into the system and check their own previous data, while only the health professionals (as well as Hejlesen and colleagues) could access all the patients' data. Furthermore, three to four patients were allocated to each member of the diabetes team (a consultant diabetologist and two nurses) as their 'contact person', which would keep up-to-date on their data and send them feedback if necessary, and which they could contact in case of any trouble during the project, either via mail or by phone. Finally, the clinicians agreed to have weekly 'Thursday meetings' to discuss current data in DiasNet as a strategy to assist each other in becoming more familiar with the system as well as the DiasNet mediated ways of analysing the data, e.g., how to identify the Somogyi effect (to be further explained shortly).

In total, eleven adult and established Type 1 patients of various age and professional background (see appendix A), most of them having a troubled history of diabetes, accepted an invitation to take part in the project. The patients' general knowledge about ICT was not an issue when inviting them. To take part in the project, the participants were asked to measure their blood sugar levels four times a day three days a week all through the project and to enter these data into DiasNet together with information on time and amount of their intake of insulin and carbohydrate.

Before starting the project, the group of eleven patients were divided into two groups, one consisting of eight patients, while the other had only three participants. This was a compromise to satisfy two groups of researchers, one being from Aalborg University (Hejlesen and colleagues), and the other being from Århus University (Andersen and colleagues). The latter group was commissioned to evaluate the effect of the project, and therefore had to interview the patients both before and after the project (cf. Dinesen et al., 2003). The consultant, however, was worried about the extra amount of work being required from the patients in the first place in terms of self-monitoring activities. And on top of that having to relate to two teams of researchers at the same time, he feared, could have a negative influence on the patients' participation. Therefore, it was agreed to spilt up the patient group into two, of which the larger group ('Group 1') was allocated to Hejlesen and colleagues to be studied by way of a 'minimal invasive' strategy.

The diabetes school was held in parallel for both groups January through February 2003 as four weekly afternoon classes of four hours each at the

[4] http://www.diasnet.dk

hospital. As traditional elements, the patients were taught general knowledge on diabetes related issues, including the physiology of hypo-and hyperglycaemia, as well as psychological factors, such as feelings of stress. As a new element in this respect, the patients were told how to carry out carbohydrate estimations, in order to be able to enter such data into the DiasNet system. Furthermore, the patients were given an introduction to DiasNet. Four aspects of this part of the teaching can be pointed out. Firstly, an introduction to the structure of the system and the rationale behind the makeup of the model. Secondly, an introduction on how to start up DiasNet as a web-based application on their home PC and how to enter data into the system (as well as how to fix conflicts with other web-based applications, such as the patients' web-based access to their bank account). Thirdly, as a way of presenting the ultimate goal of the Diabetes project, Hejlesen described two phases of using DiasNet. Avoiding too many technical expressions, Hejlesen described the intended development of the patients' role by way of a metaphor: from being a mere spectator of a football match to becoming a part of the game. In other words, the first phase would focus on improving the patients' knowledge about diabetes disease management by using DiasNet as a CAL system, as well as focusing on improving the participants stabilisation by way of intense home monitoring from the patients via DiasNet as a communication system, while in return the clinicians would devise adjustments to the regimens by using DiasNet as a decision support system. In the second phase, the patients would have obtained better stabilisation as well as the required disease management skills to use DiasNet as a decision support system on their own to carry out minor adjustments on a daily basis (only regulating short-acting insulin). This two-phase strategy characterises the underlying agenda of the Diabetes Project as a patient-centric approach to support patient empowerment in terms of a more active, collaborative, and, ultimately, more independent way of relating to diabetes and the clinicians. Fourthly, and perhaps most importantly, through ongoing plenary discussions on each of the participants' data as analysed in DiasNet. Even though this made the classes less structured, it was a key strategy to keep the patients motivated this way, as the discussions would always relate specifically to their own current situation and everyday life.

An important part of the latter aspect was to introduce the Somogyi effect, or 'counter-regulation' as it was called. While being a controversial hypothesis, which may be seen as being out-dated or lacking sufficient evidence (Lendal et al., 1995, p.98), Hejlesen refers to the Somogyi effect as a way to explain a severe divergence between the simulation and a certain pattern of SMBG. A main indication as identified in DiasNet is a markedly elevated SMBG level as compared to the simulation, following

an instance of hypoglycaemia, either as measured or as identified by the simulation. As a secondary sign to be identified in DiasNet the insulin sensitivity will be relatively low. This hypothesis was playing a major role in the use of DiasNet, not only to explain why the model sometimes does not match reality. Also, it goes hand in hand with the use of DiasNet as a philosophy to revise insulin regimens. Normally, in case of hyperglycaemia, a patient will take more short-acting insulin, or a clinician may even consider increasing the long-acting insulin level. However, according to the Somogyi hypothesis, this may only increase the risk of a new hypoglycaemia, thus resulting in new incidents of hyperglycaemia. If treated the same way over and over, such stabilisation problems may result in constantly building up the intake of insulin, which not only is expensive for the patient, but also may have unfortunate side-effects, such as an increase of body weight, as well as a decreased insulin sensitivity, which may make it more difficult for the patient to adjust the short-acting insulin. Alternatively, following the counter-regulation hypothesis, one may approach the root of the problem by decreasing instead of increasing the intake of insulin. This treatment philosophy was not only news to the patients, but to all of the clinicians as well.

To provide at backdrop for the in-depth analysis in later chapters of the patients experiences with DiasNet, I will give a few further remarks concerning the process of the Diabetes Project.

As for the diabetes school, it was successful regarding the introduction of DiasNet. The participants were generally welcoming of the new system and interested in the DiasNet mediated information concerning diabetes, e.g., the counter-regulation phenomenon and to start thinking in terms of carbohydrates. Also, they were excited to start using DiasNet even though it entailed a large amount of self-monitoring activities as well as estimating carbohydrates. By the end of the first session, one patient, ‘Bent’, who was known for having particularly bad self-care habits and practically speaking never measured his blood sugar, even said that he now felt inspired to start doing SMBG to follow the project.

Three months later, each group was invited for a midway meeting in May 2003. At this point, two patients had left the project for personal reasons. As for the rest of the participants, most of them were still entering data on a weekly basis (Hans, Jens, Karsten, Connie, Morten, and Bent), and two of the participants even entered data daily (Bjarne, Per), while a single patient had dropped down to entering data only on a monthly basis (Richard). At this meeting a number of patients put forward a critique of a lack of feedback from the clinicians. Normally, the same patients were used to only having contact with the clinicians once every three of four months. However, being a part of the project, which was presented to them as way

of keeping track of their data through DiasNet, and doing their part of the job by entering their data every week, they expected to receive relatively fast feedback on a regular basis, or an encouraging remark once in a while, even if the clinicians did not have any comments to make or adjustments to suggest. To their disappointment, the clinicians answered that they found it hard to live up to such expectations.

Another important part of this meeting was a further introduction to using the simulation and optimisation facilities in DiasNet, as well as providing a repetition concerning the identification of counter-regulations. Also, as a part of the project, the patients were asked if they were interested in experimenting with a dramatic cut down on their insulin regimen by up to 50%, due to the counter-regulation hypothesis. All nine patients agreed on this experiment. These individual experiments entailed periodically more intensive communication via DiasNet with up to six consecutive days of data instead of three, and more intensive surveillance and feedback from the clinicians following the cut down of insulin.

Even though the project was planned to finish after six months, it was not closed down until January 2004. At that time, the nine participants were invited to a final meeting at the hospital. By this time three participants still entered data on a weekly basis (‘Hans’, ‘Jens’, and ‘Per’), while three patients entered data fortnightly (‘Bjarne’, ‘Connie’, and ‘Morten’), one monthly (‘Richard’), and two had stopped entering data in the autumn 2003 (‘Karsten’, ‘Bent’). The participants had various views regarding the benefits of the system and, especially, they had mixed feelings concerning the communication with the clinicians via DiasNet. However, they all wanted to continue having access to the system, and none of the patients wanted to go back to the traditional system of only having control visits every three months. As for the clinicians, they once again told the patients that there was a lack of resources to satisfy their expectations concerning feedback on a regular basis, but that the participants were welcome to keep using the system. The clinicians also gave an explanation regarding the lack of feedback and the confusion concerning the time of closing down the project: Two other DDS projects, being the implementation of an EPR and a booking system, had brought about a heavy work load on the diabetes team, especially one of the nurses who was super user of the booking system. Furthermore, three other reasons had surfaced when interviewing the clinicians a few months earlier (Boisen & Bygholm, 2004). Firstly, the members of the diabetes team all acknowledged the fact that they did not live up to the ambition of having weekly meetings together. Secondly, they all found it hard to take time out of their daily routines to sit down with DiasNet and keep up to date with their contact persons’ data, especially because of the way the access to the

system was physically arranged: not in a closed office, which made them de facto 'available' when trying to dig into the data in DiasNet – something, which was not always an easy job for them to do in the first place. Furthermore, the consultant had stated that patients being present at the hospital or on the phone had a higher priority. Thirdly, in the same period of the DDS Project the hospital in Frederikshavn went through a time of organisational turbulence, since it was split up with a hospital in Skagen and united with two other hospitals instead, in Hjørring and in Brønderslev, to establish 'Sygehus Vendsyssel'. For some time, this turbulence left the DDS Project with a lack of essential support from the administration, something that also may have affected the Diabetes Project.

2.3 The Copability in Disease Management Project

Being interested in 'copability', as described earlier, I decided to follow the Diabetes Project in order to study this concept within a concrete context of implementing a piece of ICT equipment which was intended to enhance the patients' self-care competences. In more general terms, to enhance the users' ability 'to cope' – not with the system itself, as when focusing on 'user-friendliness' in a more narrow sense, but with their 'object', i.e., their challenge, task or interest, to be 'mediated' through this equipment. The term 'object' and its relation to the principle of artefact mediation are fundamental concepts within the school of cultural historical activity theory (CHAT), which I was looking into as a way to provide a theoretical framework for the description of the copability concept (Boisen et al., 2003; CHAT is also discussed in chapter 3 below). This initial development thus oriented the project within the research field of Human-Computer Interaction (HCI).

Meanwhile, during three visits at The Royal Bournemouth Hospital in 2002 I developed a hypothesis on how copability could be monitored, as described in (Boisen et al., 2003). The idea was to measure changes in the patients' coping when encountering stressful situations concerned with their diabetes, e.g., when being concerned with the risk of a hypoglycaemia. (The concept of coping is further discussed in chapter 4 as a way to study health behaviour). It was my impression from following the discussions at the diabetes school in Bournemouth that many diabetes patients tended to be afraid of developing hypoglycemia, and that some of the patients therefore had a tendency to be running an elevated blood sugar level to be on the safe side. A strategy that, unfortunately, can lead to severe late complications. Hence, this strategy could be associated with 'emotion-focused coping', such as 'denial', something that I found confirmed in (Lundman, 1990). Furthermore, Lazarus & Folkman describe emotion-focused coping as mostly being associated with situations, which

a person would appraise as uncontrollable, as opposed to problem-focused coping (Lazarus & Folkman, 1984, p.141). The hypothesis, therefore, was that enhanced copability would show as a decrease of emotion-focused coping strategies together with an increase of problem-focused coping, since this could indicate an enhancement of a patient's feelings of being in control, or knowing what to do.

Due to this initial hypothesis, I was thinking in terms of a before-and-after study design to monitor the changes in the patients' coping when planning how to study the Diabetes Project. In addition, I was particularly interested in studying how problem-focused coping strategies were being specifically mediated by DiasNet. To identify these specific problem-focused coping strategies, instead of making use of a questionnaire concerning coping I was planning to study the changes by comparing individual semi-structured patient interviews, before and after the Diabetes project. The idea was to combine a qualitative analysis of identifying the various coping strategies with a quantitative analysis of comparing their representation before and after the Diabetes Project. This idea, however, confronted me with a number of problems regarding my methods. (The term 'method' is used here in the sense of 'a set of procedures and techniques for gathering and analysing data', while a 'methodology' is a higher-level 'way of thinking about and studying social reality'; cf. Strauss & Corbin, 1998, p.3). The major problem being to analyse semi-structured interviews by way of statistical methods to compare the representation of various phenomena. The relative 'amount' of a given coping strategy as compared to other coping strategies in a certain transcript of an interview in terms of text, i.e., a number of passages or characters, may not necessarily mirror its representation in the daily life of that particular patient, since it could be influenced by many other factors during the interview, e.g. the flow of the discussion, or perhaps even the researcher's interest in verifying a hypothesis. Also, the diabetes school lectures could have presented the patients with problem-focused coping strategies, which they would integrate into their daily lives, and which would not be due to the use of DiasNet. What is more, it seemed that I had two interests in parallel, both to evaluate DiasNet and to construct a way of undertaking this evaluation, and it seemed that the question concerning the validation of both elements would end up in circularly reasoning.

Meanwhile, I was not interested in relating to traditional measures concerning clinical effects, such as HbA_{1c} or incidents of hypoglycaemia. The reason was that since the patients were cut down on insulin by op to 50% due to the clinicians' use of DiasNet as a decision support system, it was impossible to study the metabolic effect related to the patients' use of

DiasNet. This way, the project was taking steps away from the common focus of the medical research field when evaluating projects like the Diabetes Project (cf. discussion above in chapter 1). Instead, the CID project was developing into a theoretical consideration on the development of a concept to describe artefact mediation of health behaviour changes, having the test of the coping hypothesis as a sub-goal. Furthermore, along the idea concerning coping, I was also considering the concept of 'motive' within CHAT as a way to study whether the patients would develop feelings of urge in doing self-care during the Diabetes Project. Still, to develop these thoughts I was planning to study changes of the patients' thoughts and behaviour in a before-and-after study design building on individual interviews.

Unfortunately – or perhaps luckily – due to the minimal invasive strategy, I was not allowed to have individual interviews with the patients in Group 1, which was the group I was allocated. Instead, I was allowed to observe each of the four diabetes school sessions, as well as the midway meeting three months later and the final meeting (held in January 2004). Yet, to have some before-and-after data, I asked the patients to answer the IDDM Diabetes Self-Management Questionnaire from Ipswich Diabetes Centre (Day et al., 1996), which I had translated into Danish (see appendix B). The questionnaire was focusing on various areas of 'self management' skills and was sent to all the participants (in both groups) before the start of the project (January 2003) and again by the end of the project almost a year later (December 2003). In addition, I was allowed to have a one-hour group interview with Group 1 as a part of their fourth diabetes school session (February 2003), one month after the start of the project. As preparation for this interview, I used the answers to the questionnaire as well as my observations during the sessions. Being interested in coping, I asked them if they could tell me about a recent situation in their daily lives, which they found difficult, and what they did then (Lazarus & Folkman, 1984, p.317). But my main concern was not to intervene with too many questions when eliciting patients' perceptions. Instead, I wanted to exploit the nature of a group interview to promote a permissive, non-threatening environment and to have as much flow as possible in the discussion between the patients themselves (Twohig & Putnam, 2002; Malterud, K. et al, 1997).

As it turned out, I found it difficult to have a flow in the discussion, while at the same time to ensure that my topics were covered. Furthermore, while three of the patients were particularly talkative, two of them almost said nothing. One of them, I had noticed, was quite talkative in less formal settings. Malterud warns against group interviews to elicit personal views on sensitive topics (Malterud, K. et al, 1997), and therefore it could

be difficult for some of the participants to be honest about their coping behaviour in that setting. Also, the presence of the dietician may very well have influenced the process for the same reason, something I now consider a major blunder – not only because she was eager to answer all my questions and to comment on the patients' answers until she was kindly asked not to take part in the discussion! In combination with the fact that the group interview was carried out after three weeks of diabetes school classes and DiasNet use, I found it hard to use this group interview as my baseline data concerning coping.

For all these reasons, the minimal invasive research strategy, the fate of the group interview, as well as the method problems, I eventually had to let go of the idea of testing my coping hypothesis as a way to monitor copability. Instead, I set another goal merely to contribute to the understanding of the field of computerised diabetes disease management. Choosing this new goal meant taking a final step away from a natural science like way of thinking, and moving closer to the approach of the monitoring research method as described above concerning the analysis of 'social experiments' from a side-line position. Even though my educational background primarily was within humanities (which may be seen as focusing on ideographic, rather than nomothetic knowledge as within natural sciences), this was not an easy step to take. In trying to understand this change of thinking I wrote the following note:

> Perhaps good science not only means being in control... for instance, being in control of what happens during an experiment in testing a hypothesis. – Still, in doing research one is generally advised to look for 'black swans', i.e., findings to falsify some general statement. But I no longer know what is figure and what is ground. It seems that I need to place myself 'out there' at the deep waters of diabetes disease management together with the patients, the health professionals, and the system designers. It seems that I need to go fishing for some time to find out what kinds of fish are out there. I may need to 'lose control' not knowing what to look for or what to do with whatever I find as an alternative and perhaps more profound way of being 'objective' (cf. Kvale, 1997), instead of being open only to certain aspects, which are identified beforehand, e.g., in terms of certain coping patterns. [eb, 2003]

In the meantime, I was allocated to another research project looking into the implementation of the health informatics systems within the DDN Project (Boisen & Bygholm, 2004). Since the DDS Project took up a major part of these projects, this gave me the opportunity to study the context of the Diabetes Project more closely. As a part of this research I also interviewed the diabetes team in December 2003. Surprisingly, when asking the doctor what he thought the patients had learned during the project,

he said: 'I have no idea... I thought you could tell me!' This inspired me to focus more on the patients' learning and the question of empowerment.

The new orientation of the project, therefore, was to contribute to the understanding of the field of computerised diabetes disease management by way of an explorative and qualitative study into the patients' experiences of using a disease management system (DiasNet) as a part of their daily lives, and whether this enhanced their ability to 'cope' in terms of which ever aspects would appear to be relevant. While trying to be as open-minded as possible, I knew that I would like to study the following issues: coping, which I later decided to consider a way to define health behaviour (see chapter 4); learning; artefact mediation; and 'motive', i.e., what 'drives' the patients in doing self-care activities.

2.3.1 Collecting data in Frederikshavn

I decided to base the study on individual in-depth interviews with all nine patients, integrating all the other empirical sources as preparation. Thus, to device a personalised interview guide for each semi-structured individual interview (see appendix C) I collected empirical data from the following sources: the patient's answers to the questionnaire at the beginning and at the end of the project; my observations during the diabetes school and the midway meeting; the group interview; the individual interviews with the clinicians; a thorough study of the patient's data in DiasNet; as well as all available data from the hospital concerning the development of each patient's weight and HbA_{1c} from the beginning of the project to the time of the interview. I also devised a basic interview guide listing a number of topics, which I would like to cover concerning daily life with diabetes, partly inspired by a similar Danish study on diabetes disease management (Hølge-Hazelton, 2002), and partly inspired by similar studies within other fields of disease management, especially concerning the impact on social life when suffering from 'invisible' diseases (Hallberg & Carlson, 1991; Hofgren et al., 1998). And due to my interest in 'motive' and 'empowerment' I also added questions to the list about what drives them when dealing with diabetes day after day; whether they would consider the project worthwhile even though it did not lead to any clinical improvement; and what they would say, out of their life experience, to a young person that had just being diagnosed with diabetes. As an interview strategy, I was planning to elicit as much contextual information concerning their disease management by way of narrative interviews, as advised by (Lazarus and Folkman, 1984; Lazarus, 1999). The aim was to encourage the participants to tell stories by asking 'when', 'where', 'what', and 'how' questions, but avoiding 'why' questions (as instructed at a course on narrative interview techniques; also cf. Kvale, 1997).

Likewise, I was inspired by Flyvbjerg and his narrative research methods (Flyvbjerg, 1998; 2001), as well as his method of 'critical interviewing'[5]. I therefore decided to refer to the empirical data, e.g., data from DiasNet, during an interview even at the risk of not being able to keep up a non-threatening atmosphere all the time, e.g., by confronting a given patient with embarrassing information: This may be considered a controversial and risky interview strategy, which is normally not recommended (e.g., cf. Maaløe, 1999).

After receiving informed consent from the participants, all nine patients were I interviewed in their home during Spring 2004, a little more than a year after the diabetes school. The interviews most often lasted around 90 minutes and were recorded on tape. The tapes were transcribed verbatim by myself a few months after the final interview resulting in close to 300 pages of text in total. The transcripts were anonymised and imported into NVIVO 2.0, being a caqdas environment for coding qualitative material. This material was then my basis for carrying out the explorative study in this environment.

2.3.2 Coding, categorising and clarifying concepts

The coding was carried out after the final interview was transcribed summer 2004. To begin with, all interviews were coded using an open coding strategy, resulting in close to 200 'free codes' (and 'NVIVO codes') for each interview. Thus, each code was highlighting a part of the text (character by character) and was conceptualised by a few words (the number of these words being delimited by NVIVO 2.0). The coding process was inspired by 'grounded theory' (Strauss & Corbin, 1998), the core process of which is conceptualising, or, creating 'in vivo codes':

> In conceptualizing we are abstracting. Data are broken down into discreet incidents, ideas, events, and acts and are then given a name that represents or stands for these. The name may be one placed on the objects by the analyst because of the imagery or meaning they evoke when examined comparatively and in context, or the name may be taken from the words of respondents themselves (ibid., p.105).

The core idea is to put away well-known concepts and to discover new categories, and eventually theories, being grounded, not in previous knowledge, but in the data. 'The data are not being forced; they are being allowed to speak.' (Ibid., p.65) There are two essential operations in this process of developing a grounded theory: asking questions, and making

[5] Interview with Bent Flyvbjerg during his course on narrative research methods, 13.11.03.

comparisons (ibid., p.73). Concerning the latter, constant comparisons is about clarifying the categories, not only when sorting the 'in vivo codes', comparing 'incident' to 'incident', but also when solving the theoretical problems being a part of this process, i.e., theoretical comparisons in terms of identifying the properties and dimensions of the categories and sub-categories. As for the first principle, asking 'good questions' is a highly creative process, which, they say, may 'sometimes depend on luck, but more often they are prompted by relevant knowledge, a sense of "something is missing here," and (more importantly) sensitivity to what the data really are saying' (ibid., p.75). Indeed, finding the core question, or the proper focus of the inquiry, is what research is all about (cf. ibid.). Perhaps this core idea of this approach can be described in the way that the focal question of the inquiry is not merely applied by the researcher in a top-down manner, but somehow produced in a dialogue between the researcher and the data (and knowledge about the context of the data) in a bottom-up process. This ideal of grounded theory has been criticised by Alvesson & Skjöldberg as overlapping with positivism, which regards empirical data as (relatively) theory-free (Alvesson & Skjöldberg, 2000). However, due to the core role of the researcher's 'sensitivity', I like to think about the essence of this approach as being more closely related to non-positivist approaches. For example, their concept of being sensitive to finding good questions ('something is missing here') may resemble what the non-positivist Polanyi has described as the human capacity for 'tacit knowing', which the scientist sets out to explore to make more explicit, not knowing exactly what to look for, but still being able to focus the inquiry (Polanyi, 1966). Also, grounded theory have similarities with post-modern thinking about the social construction of knowledge, as exemplified by Kvale explaining that being 'objective' as a qualitative researcher is about establishing a conversation with the object of the inquiry, i.e., a process of interpersonal relations in which knowledge of the object is produced (cf. Kvale, 1997).

Building on these core principles, grounded theory was functioning as a 'regulative ideal' for my analysis of the interviews. Firstly, in terms of trying to be as open as possible toward the material – as well as my own 'sensitivity' to the focal issues in it. Secondly, in terms of the principle of constant comparison. However, I consider my analysis being only inspired by grounded theory, as I was aware that I had already decided on certain concepts to look for before analysing the transcripts, and even while preparing for the interviews. Also, I carried out all the interviews before any coding took place, and thus the selection of the interviewees were not influenced by any ongoing analysis of the material. Furthermore, my work was not organised in accordance with the four steps being

open coding, axial coding, selective coding, and theoretical coding (Brender, 2006) [6]. If these four concepts at all apply to my analysis, they were mixed up as various 'stances' toward the material, not as a sequence of stages in what turned out to be a highly chaotic and long-drawn-out process from autumn 2004 to autumn 2005.

Hence, only after the initial open coding process in the autumn 2004 the hard work began as a cyclical, almost Sisyphosian, process of categorising the codes, noticing conceptual problems in this process, clarifying concepts through theoretical investigations, re-coding in accordance with some conceptual clarifications, noticing new conceptual problems, and so forth. In over-all terms this process can be described as consisting of three phases. First of all, during the initial conceptualisation process I had often made use of coping terms. Therefore, in a first categorisation phase all the free codes were thoroughly analysed to categorise incidents of coping in terms of (a complex system of) various coping types. Furthermore, the nine interviews were once again coded in order to account for every incident of coping. I also decided to view these coping incidents as a way to identify and analyse health behaviour, and therefore to base my further analysis of the integration of DiasNet into the patients' health behaviour on these incidents. Next, a second categorisation phase was looking into these text passages (the incidents of coping) in order to identify and categorise artefact use according to the artefact concepts described in chapter 3. Thus, this analysis also points out cognitively mediating artefacts at artefact levels above the basic artefact level of DiasNet and other (more or less) tangible tools. Thirdly, an artefact can mediate many purposes, and in effect, have many different appearances as a tool. Since DiasNet is a highly complex tool compared to, e.g., SMBG meters or insulin pens, DiasNet's toolness appears as various purposes of using DiasNet, or various 'use forms'. Four use forms were pointed out as the result of this final phase of categorisation.

It is difficult to give a detailed account of each of these three phases. As an example I have tried to account for one of them concerning coping (see chapter 4). However, concerning the ideal of grounded theory there where differences between these three phases. Whereas the categorisation of use forms was mostly data-driven, the artefact analysis was mostly theory-driven, while the coping analysis was an even mixture of both (see

[6] Open coding, i.e., conceptualising; axial coding, in which the generated concepts are organised into categories and sub-categories and their definitions are clarified; selective coding, in which the relationships between the concepts are identified as well as a central concept; theoretical coding, in which a hypothetical model is worked out to explain the phenomena observed and their interrelations (cf. Brender, 2006).

figure 2.1). In other words, when sorting the 'incidents' the theoretical comparisons concerning artefacts were heavily guided by theoretical considerations concerning the relationship between Engeström's concepts on artefacts and three other conceptual hierarchies (cf. chapter 3). As for coping, the theoretical comparisons were informed by the data as much as by coping theory as well as by research on coping within diabetes (chapter 4). And finally concerning use forms, the theoretical comparisons were based on (my sensitivity to) data on the patients' way of approaching DiasNet as a tool (chapter 5).

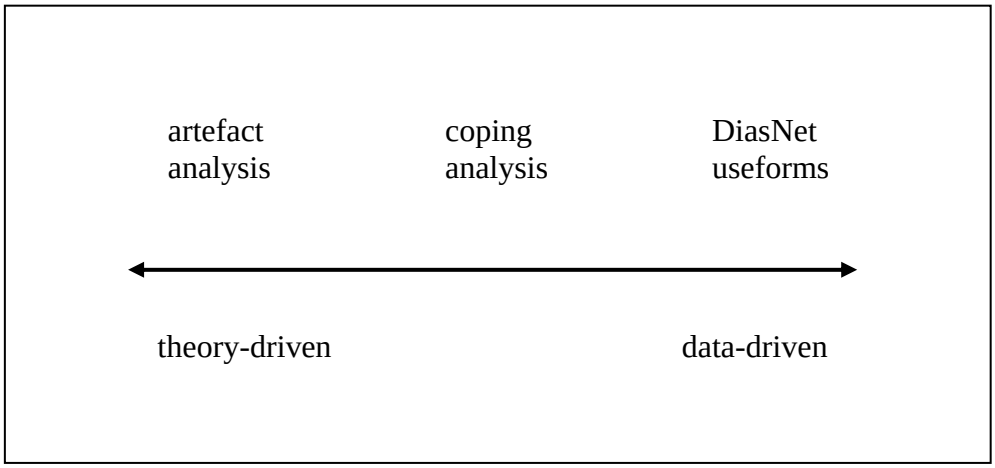

Fig. 2.1: Three sets of categories being the results of theory-driven and/or data-driven analyses.

It later occurred to me that all three sets of categories could be integrated in terms of an 'interface analysis' of DiasNet, which seeks to clarify how DiasNet mediates the health behaviour of the patients. The concept of interface is here understood in terms of mediation, i.e., something between a subject and an 'object' (and not something between a subject and the computer technology on which DiasNet is based, or DiasNet itself seen as an object). Furthermore, the internal relation between the three sets of concepts could be illustrated by a triangular model of artefact mediation within CHAT (see Figure 2.2, next page).

The idea, then, is to characterise the subject in terms of his or her coping behaviour, whereas the object is characterised as one of the four use forms, or purposes using DiasNet, while the artefacts (mediating a given coping behaviour being oriented toward DiasNet in terms of a certain use forms) are characterised in terms of various artefact levels.

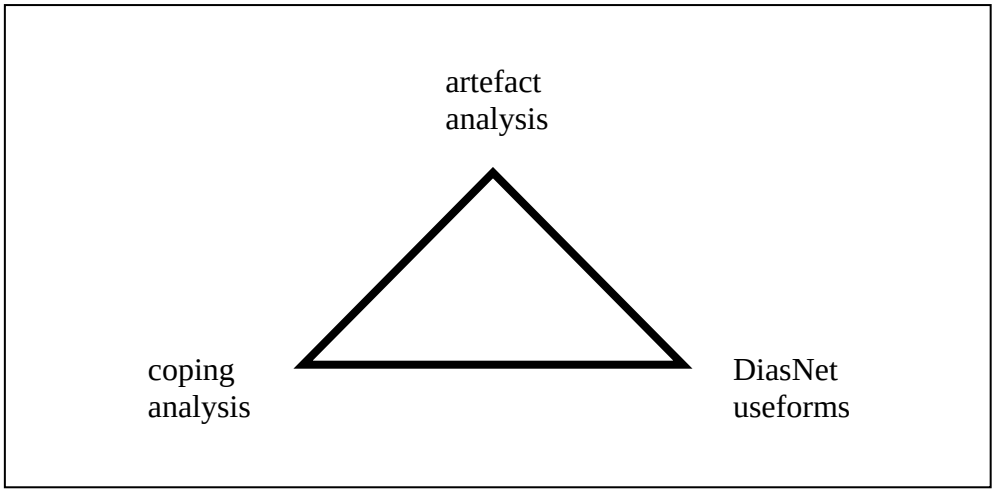

Fig. 2.2: The three sets of categories being the results of theory-driven and/or data-driven analyses.

As described above (chapter 1), one of the essential problems in developing and implementing a diabetes disease management system like DiasNet is its evaluation. The following study both includes the development of a description method, as well as an evaluation of DiasNet in accordance with this method. My aim is to present a way to evaluate DiasNet's potential contribution to meeting the challenges of patient participation in IDDM disease management by way of these three sets of categories. This description, therefore, will draw on three kinds of analyses of the nine patient interviews concerning the their coping, DiasNet and its related artefacts, as well as their purposes of using DiasNet (its use forms). As an evaluation, this descriptive 'interface analysis' is then used normatively by relating it to specific goals of implementing DiasNet, as a 'copability analysis'. Hence, the analysis further describes the usefulness of DiasNet in terms of how it is integrated into dealing with the disease as a part of the patients' everyday life, both in terms of 'adoption' and 'patient empowerment'.

2.3.3 A note on the statistical method of analysis and its influence on coding

A final note on methodical considerations concerns my method of building the discussions of adoption and empowerment on analyses based on the statistical facilities of NVIVO 2.0: This was done by way of queries consisting of combinations of codes pointing to strings of text being coded by categories from the three sets of concepts. As statistical data I primarily used the number of patient interviews in which a certain combination was found. Counting the number of patients representing a phenomenon may seem a safe thing to do. However, I also sometimes used

the number of times it appeared in the material in order to rank coding combinations, which appeared in the same amount of patient interviews. Doing this is more controversial. It is not uncommon to combine qualitative and quantitative approaches, however, it would then typically be by way of devising a questionnaire (partly) based on a qualitative study identifying research questions and concepts. To mix the two approaches the way I do may be considered problematic for a variety of reasons. For instance, if one interviewee is very talkative, then the coping types he discusses will be representing more characters of text in the material than the coping types of a less talkative person, and this in itself does not mean that the coping types of the talkative person are more important than the second persons' coping types. One might handle such problems by way of statistical methods (normalisation). However, from a more principal point of view some would conceive of such efforts as a misuse of methods. They would deny the mere possibility of talking about statistical representation in a qualitative study in the first place, saying that qualitative research interviews are suitable for revealing phenomena and exploring their nature, but not to measure their statistical representation. Also, they would point to the nature of a qualitative, semi-structured research interview in which the interests of the researcher as well as the interplay between him and the various interviewees will have great impact on what is being discussed and for how long. Still, being aware of such problems I decided to guide my ranking, secondarily, by comparing the distribution of the various codes in terms of the number of times they were used. If a certain code is used one hundred times, while another code only appears two times in the material, I will argue that this indicates that the former is more commonly distributed than the latter – in the material. This does not necessarily mean that the former code, say, concerning a certain coping type, is also a more common way of coping among the interviewees than the latter coping type. However, this is what I have assumed based on the assumption that what took up space during the interviews reflects what was important to discuss – while keeping in mind not to take minor differences in the distribution of the codes too seriously. Also, having in mind during the coding phase that I was later going to analyse the statistical distribution of the codes, I believe, influenced the coding phase in a positive way. Since it was important for my analysis the number of times a certain code was used, I had to use every code every time it was applicable, something which is not necessary in case only the mere existence of a phenomena is important. This way, the codes were used meticulously, and, I believe, thereby confronted with more material, which, in turn, provoked a number of situations, which would sometimes reveal a need of further conceptual clarifications. Also, when finally studying the combinations of codes as done concerning the What artefacts and their

relation to both codes on use forms and coping types, I was confronted with my coding from many angles over and over again, and this process also contributed to the clarification process. Hence, it is my contention that, due to the cyclical process of coding and conceptual clarification, the enhanced requirement for coding the material in a meticulous way improved the quality of the focal outcome of the qualitative research interviews, i.e., the conceptualisation of phenomena.[7]

[7] The discussion of this issue could be taken further as a contribution to the current research in exploring the potential of CAQDAS and its impact on qualitative research methodology (e.g., Coffey et al., 1996; Lee & Fielding, 1996; Fielding, 2000).

3 Artefacts, learning, and activity

3.1 Studying the integration of mediating artefacts and the development of human activity

The school of Cultural Historical Activity Theory (CHAT) has its roots in the work of the Russian cultural-historical psychology in the early 20th century (Vygotsky, Leontiev, and Luria). Founded on Marxist philosophy, CHAT provides a framework of principles for studying the structure of human activities in their social, organizational, and technological context, while at the same time having the development of human activities as its fundamental issue. My motivation for taking this approach as the theoretical stance on studying the usefulness of DiasNet is two-fold. First, it suits my purposes of studying usefulness in terms of the integration of a new piece of technology into the daily lives of the diabetes patients (the adoption theme), as well as to talk about this integration in terms of learning and development (the empowerment theme). Second, much interest is currently drawn to CHAT within the field of Human-Computer Interaction (Bødker, 1987; Engeström, 1996; Nardi, 1996; Collins et al., 2002; Korpela et al., 2002; Mwanza, 2002). As a brief introduction to the principles of CHAT I will take a look at three sets of concepts of particular importance. Later, I will introduce the goal of this chapter as a study of the relationship between three conceptual hierarchies concerning artefacts, learning, and activity.

Central to the cultural-historical approach of activity theory is the concept of *tool mediation* (Kaptelinin, 1996). This notion of mediation dates back to one of the founding fathers, the Russian psychologist Lev S. Vygotsky. In trying to establish the foundation for a cultural historical psychology, Vygotsky describes higher psychological processes as mediated by two types of artefacts, tools and signs, as illustrated below (Fig.3.1).

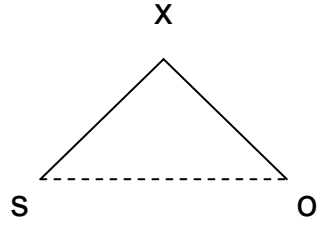

Fig. 3.1: A model of the principle of mediation, adapted from Vygotsky 1978, p.41.

This model illustrates the mediated relationship between subject and object as mediated by auxiliary means (a tool or a sign). As the model illustrates, there is no direct relation between subject and object. Hence, the way a 'subject' is approaching his 'object' (i.e., what he is 'working on') is both facilitated and constrained in terms of the tool. Thus, as our tools are products of our culture, both our activities and our thinking about those activities will be influenced by cultural material. A related concept is *internalisation* as a term for the way mental processes are derived from external actions. Cognitive processes of human beings are structured through practical activities in a social setting by way of making inter-subjective actions 'intra-subjective' (Kaptelinin, 1996). This concept is also closely linked to the idea of a *zone of proximal development*, being the distance between what, e.g., a child is able to accomplish when it is on its own and when it is in collaboration with an adult or a tool (Engeström, 1996). Also, a related concept here is *the formation of functional organs* as a term for the phenomenon that human abilities are extended by way of external components. Phenomena like an artist-with-his-pencil or the chauffeur-with-his-vehicle are examples of functional organs representing abilities that the human being would not otherwise develop or posses, and which will be integrated parts of the identity of the artist and chauffeur.

Concerning the structure of human activity, another important set of concepts is *activity*, *action* and *operation*. In his book from 1975, 'Activity, Consciousness, and Personality', A.N. Leontiev, a student and co-worker of Vygotsky, suggests this set of concepts in providing a psychological analysis of the general structure of the "units" of human activity (cf. Leontiev 1978, pp.62-74). Hence, a description of a given (human) activity should distinguish between three analytical levels, or aspects, being 'operations', 'actions', and 'activity', corresponding to 'conditions', 'goals', and 'motive', respectively (see Fig.3.2).

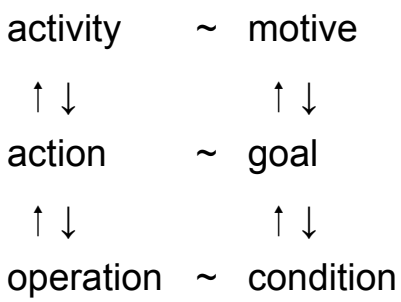

Fig.3.2: Three aspects of activity (as illustrated by Kuutti, 1996)

An activity consists of a series of actions directed at specific goals, and actions are carried out in a series of *operations* determined by *conditions*. Goals are subordinate to, and different from, motives, and operations are subordinate to, and different from, actions. If you are going to make a pot of tea (goal) to sit with some friends (activity) and you find out that the stove has broken down, you will perhaps choose to boil the water in a microwave, instead (operation). Hence, activities are oriented to *motives*, i.e., an object to be transformed in accordance with a desired outcome. In other words, an 'activity' seen as a unit is being distinguishable from another activity in terms of its 'motive', i.e., an object that satisfies a need initiating the activity (cf. Leontiev 1978, p.62). Concerning these analytical concepts it is important to notice that they are not meant for analysing the units of human activity into its discrete elements. On the contrary, what Leontiev wanted to provide is a method of analysing activity in terms of internal relations. In other words, each isolated 'activity' is to be seen as a whole having certain aspects to be described by his analytical concepts.

> The special feature of the analysis that serves to isolate them [the "units" of activity, eb] is that it does so not by means of breaking human activity up into elements but by disclosing its characteristic internal relations. (Leontiev 1978, p.67)

A third set of concepts is *development* and *contradiction*. The Finnish educational theorist Yrjö Engeström describes how the identification of contradictions in a complex organization can be used in order to focus on how to restructure the organization to become more effective (Engeström, 1996). Contradictions between members in the organisation, or breakdowns in a working process, are thus not seen as negative obstacles, but as chances of focused development of an activity system. In his work from 1987, Engeström presents the model below (see Fig. 3.3, next page) to describe such 'expansive learning' in terms of the model below, being an expanded model of the one presented by Vygotsky. Engeström's and his expanded model has become highly influential within HCI to the extent where the analytical power of CHAT almost exclusively is identified with this model (e.g., Collins et al., 2002; Korpela et al., 2002; Mwanza, 2002).

In presenting his concept of 'expansive learning', Engeström (1987) draws on the integration of three conceptual hierarchies: one on learning levels (Bateson, 1972/ 1999), one on artefacts (Wartofsky, 1973), and one on activity (Leontiev, 1978). This idea I find particularly interesting, as it provides a way to discuss artefact mediation in terms of learning levels, which is useful in analysing the integration of DiasNet in self-care (the

adoption theme), as well as DiasNet's potential in supporting an expansion of self-care as an activity (the empowerment theme).

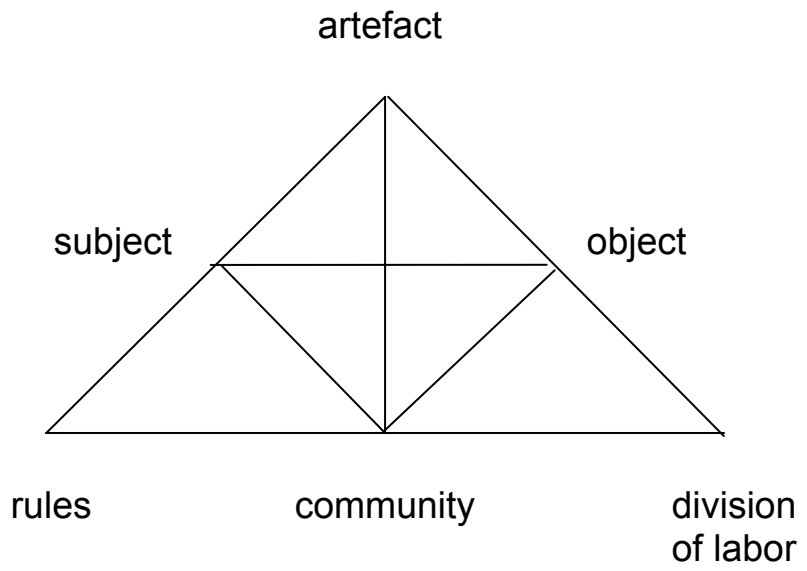

Fig. 3.3: Engeström's expanded model of the structure of human activity systems (Engeström 1987, p.78).

In what follows, I will therefore present an in-depth discussion of this idea in order to clarify how these concepts were understood during the coding of the patient interviews. In my discussion, I will also take account of Engeström's paper from 1990, 'When is a tool?', in which Engeström expands Wartofsky's classification of artefacts into four categories – an expansion, which might destroy the isomorphism of the conceptual hierarchies (Engeström, 1990). Meanwhile, in the text from 1987 Engeström also expands Bateson's classification into four categories. And even though Engeström does not mention Bateson in the text from 1990, I will argue that these expanded classifications match.

Nevertheless, I do not agree on the way Engeström conflates the conceptual hierarchies. Building on a close reading of the way Bateson originally discussed the learning levels, my discussion will lead to a presentation of how, in my view, the three sets of categories could be integrated. My goal of this detailed discussion is to provide a clarification of concepts to analyse the usefulness of DiasNet as a mediating artefact in proficient self-care.

3.2 Logical types of learning levels

Gregory Bateson, a British anthropologist being one of the most influential systems thinkers of the twentieth century, whose research crossed the disciplinary boundaries of cybernetics, animal communication, ethnography, psychology, and biological evolution, did not write much about artefact mediation. He did, however, use the famous example of the blind man and his stick in order to explain his view on the mind.

> The elementary cybernetic system with its messages in circuits is, in fact, the simplest unit of mind [...] Suppose I am a blind man, and I use a stick. I go tap, tap, tap. Where do *I* start? Is my mental system bounded at the handle of the stick? Is it bounded by my skin? Does it start half-way up the stick? Does it start at the tip of the stick? But these are nonsense questions. The stick is a pathway along which transforms of difference are being transmitted. The way to delineate the system is to draw the limiting line in such a way that you do not cut any of these pathways in ways, which leave things inexplicable. If what you are trying to explain is a piece of behaviour, such as the locomotion of the blind man, then, for this purpose, you will need the street, the stick, the man; the street, the stick, and so on, round and round. But when the blind man sits down to eat his lunch, his stick and its messages will no longer be relevant – if it is his eating you want to understand. (Bateson 1972/ 1999, p.465)

This way of describing the phenomenon of mind processes is very similar to fundamental notions within CHAT. As Cole & Engeström writes in an introduction to CHAT, while drawing on the same classical example:

> Analysis of the mind's focus must include not only the man and his stick, but also his purposes and the environment in which he finds himself. (Cole & Engeström, 1993, p.13)

In this example, the blind man's object would be to 'find his way in the street', and the artefact would be the stick mediating information about the pavement as well as the blind man's operations in finding his way, the sweeping and tapping movements of the stick. Furthermore, due to the principle of 'cybernetic circuits' the human mind is considered immanent in both internal and external pathways of information. In supplement to his stick the blind man also has internal pathways of information in terms of relevant parts of memory, for instance, his ideas about the actual environment, as well as the computational faculties residing in his brain[8].

[8] As a case in point, the 'blind man and his stick' example proliferates within phenomenological thinking. Before Bateson, this example was discussed, at least, by Maurice Merleau-Ponty (1945) and Michael Polanyi (1966). Bateson, however, does not provide any reference for his inspiration. In Bateson's view, both the reader and

In making these initial observations of the thinking of Bateson, my point is to show that it seems compatible with a basic principle of CHAT concerning mediated cognition. Also, by emphasizing his cybernetic thinking my point is to announce the angle from which I will interpret his learning theory: instead of merely memorising the examples and features which Bateson uses to describe the various learning levels, I will focus on the underlying method used in establishing these levels. And here I have tried to sharpen my analysis by way of an underlying information processing paradigm of cognitive science, which, like Bateson's learning theory, has cybernetics and information theory as its theoretical origin: in what follows, learning is seen as changes in information processing, and learning levels as logical types of such changes.

3.2.1 Learning as changes in information processing

For Bateson learning levels are to be explained in terms of *changes* (Bateson 1972/ 1999, p.247), not levels of performance. An organism can be perfectly attuned to its environment, taking account of a vast amount of information, and still be at 'level 0' in terms of learning. However, 'Learning 0' does not mean that the organism learns nothing or that it does not change at all. It does. At this level 'learning' means acquiring information about the environment, as when one 'learns' what time it is by asking someone. And 'change' at this level applies to the changes of the 'state' of the organism due to its processing of information (cf. ibid., p.248-9). What does not change at this level, though, is its way of processing information. As Bateson states, 'zero learning is characterized by specificity of response, which – right or wrong – is not subject to correction' (ibid., s.293). Given the same information the organism would respond exactly the same way.

If the organism at some point responds differently to the exact same information, this means that it has changed its way of changing. Thus, a meta-change has occurred, a change of a higher *logical type*[9]. This type of change is called 'Learning I'. Bateson defines Learning I as a 'change in specificity of response by correction of errors of choice within a set of al-

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himself as the author are being parts of a mental system that extends the individual mental systems by having these as its pathway. In closing a paper on epistemological issues Bateson makes the wish that his ideas represented in the paper may live on in the reader. From being immanent in his own mind when writing about them, they can become immanent in the reader. 'May they survive – if true.' (Bateson 1972/ 1999, p.471)

[9] Concerning this fundamental concept, Bateson is inspired by Russell & Whitehead's hierarchy of logical types, which can be exemplified by the difference between information about a certain item and information about the class of such items.

ternatives' (ibid., p.293). If, for instance, I visit a foreign country where the traffic light system is working differently, red could mean 'walk' and green could mean 'stop'. If I, in spite of this difference, continue to follow the accustomed way, I will commit an 'error of choice within a set of alternatives'. Correcting this error according to the foreign system will then be an example of Learning I. And after this correction, I will, hopefully, continue to interpret the traffic lights the same way during my stay. In this instance, doing so will only qualify as Learning 0, taking account of information and responding accordingly. I would not be said to be operating at learning level I even though I had changed my way of interpreting traffic light signals due to an instance of Learning I.

If learning I is a change in the process of Learning 0, then learning II is a change of yet a higher logical type, i.e., a change in the way of changing the way of changing when given some information. If Learning 0 corresponds to taking account of some piece of information, e.g., learning from a sign, then Learning I is learning a new sign (or more precisely, learning to learn from a new sign). In effect, learning II is 'learning to learn' new signs to learn from (cf., ibid., p.249). In Bateson's definition Learning II 'is a change in the process of Learning I, e.g., a corrective change in the set of alternatives from which choice is made, or it is a change in how the sequence of experience is punctuated' (ibid., p.293). That which is in question relates to the set of response alternatives as a whole, not the various alternatives in discrete terms. At first reading this may seem confusing. I will therefore discuss two examples given by Bateson in order to illustrate instances of Learning II.

Normally, when training a dog the trainer does not want the dog to change behaviour, from time to time, when given the same signal. Bateson, however, describes an experiment he undertook with a dolphin where the goal was to see if the dolphin was able to change behaviour from training session to training session when given the same signal (ibid, pp.271). Instead of reinforcing the same display of behaviour, the dolphin was reinforced to change display of behaviour. The procedure for establishing this pattern of reinforcement consisted of two parts. The first part of the procedure was to wait for the dolphin to show 'conspicuous' behaviour, for instance raising her head above the surface. Seeing this, the trainer would then blow a whistle and give the dolphin a fish. If the dolphin repeated the same movement once again, it would be given another fish as reinforcement. This procedure was used for public demonstrations of 'operant conditioning', i.e., learning I within dolphins. The next time the dolphin would enter the scene it would expect another fish when showing the same behaviour as before. Then, the next part of the training procedure was not to give reinforcement. The dolphin would only get re-

inforcement when displaying behaviour that had not been reinforced at prior training sessions. Thus, the trainer would watch for the dolphin to display a new example of conspicuous behaviour, e.g., a slap with the tail indicating annoyance. As before, the trainer would blow the whistle and the dolphin would be given a fish as reinforcement for displaying this new movement. However, these two instances of learning I do not add up to learning II. The third time the dolphin entered the scene it would repeat a reinforced movement and expect to get fish – but, of course, would not get one until it, by chance, displayed a new piece of behaviour. At this point the dolphin would have been through three different instances of reinforcements, three different *contexts*, each established by a number of elements including the tank for training sessions, the sound of the whistle, the fish, and its own specific movement. So, to display a new piece of behaviour intentionally, in order to get fish, it would have to take account of the overall context of these three contexts. Thus, the dolphin would have to create a new *punctuation* in which each training session was not a whole in itself, but only a part of a context at a higher logical level, a context of contexts – established by the tank for training sessions, the sound of the whistle, the fish, the series of training sessions and its own *change* of specific movements. In the experiment reported by Bateson it took fourteen training sessions for the dolphin to find this pattern and to take account of the context of contexts. Doing this meant accomplishing an advancement from learning I to learning II. Bateson describes a number of indications that a new kind of change was actually taking place, and that the dolphin did not merely show chance behaviour as it had done before. After the fourteenth training session the dolphin was very excited. When it entered the training tank the fifteenth time, it displayed a whole series of conspicuous behaviour, some of which were never before observed within this species[10]. Bateson notes that the type of challenge the dolphin was facing can thus lead to creativity. He also notes, however, that being faced with changes in reinforcement patterns at learning level I leads to painful frustrations and maladjustments. Several times the trainer had to break the second rule of the experiment in order to preserve the relationship with the dolphin.

This latter aspect is illustrated by another example given by Bateson when illustrating learning II. I would like to discuss this second example,

[10] Whether Bateson believed that the dolphin actually had reached a higher learning level may not be clear when reading 'Steps to an Ecology of Mind' (Bateson 1972/ 1999), but he makes it quite clear in his book 'Mind and Nature' from 1979 (Bateson 1979, p.132) that the dolphin reaches a learning level, which is a single step above a demonstration of operant conditioning.

because Bateson appears to be inconsistent in his description of it in terms of which learning level is in question. Throughout this discussion it is my goal to clarify my understanding of the concept of learning levels and how it applies to my study concerning learning artefacts as applied to diabetic patients.

In an experiment a dog was driven to severe frustration by being confronted with changes in reinforcement patterns that in some respects is similar to the case of the dolphin. First, in a classical Pavlovian setting the dog was trained to distinguish between two geometrical shapes, a circle and an ellipse (ibid., p.296-7). When this skill was thoroughly trained, the experimenters began to make the shapes more and more similar in order to make it increasingly difficult to distinguish between them until, finally, the shapes were identical. At this point the dog started to show symptoms of severe disturbance. In Bateson's discussion of this experiment he emphasizes that at this point 'the structure of the context is totally changed'. The dog could no longer distinguish between the shapes. The trained skill had become inappropriate in this new context. Unfortunately, unlike the dolphin, the dog was unable at this point to develop a new skill appropriate for the new context. Instead, the dog appeared to be fixated in the former contextual framework. As Bateson notes, 'a naive animal' [i.e., one that was not trained to distinguish between the two shapes, eb] would not show signs of disturbance when put in the new context. Bateson also notes that 'the disturbance does not occur in absence of many context markers characteristic of the laboratory situation.' (ibid., s.296-7). Now, what Bateson concludes from this in terms of learning levels is that 'Learning II is a necessary preparation for the behavioural disturbance' (ibid., s.297). He further explains that, '[t]he information, "This is a context for discrimination," is communicated at the beginning of the sequence and *underlined* in the series of the stages in which discrimination is made progressively more difficult. The context markers (*e.g*., the smell of the laboratory and the experimental harness) now become misleading because the animal is in a situation which demands guesswork or gambling, *not* discrimination (ibid., p.297).' However, in my view, this conclusion is not in accordance with the above example concerning the dolphin. Let me explain why.

The cases of the dog and the dolphin have similarities. Both animals are trained in terms of Learning I, and both are put in the wrong about what they have learned at this level. And it seems that both animals are expected to change response when given the same signal. But there are some significant differences. Regarding the case of the dolphin I mentioned how the procedure of the experiment had two elements, or two 'rules', each applying to a certain context. The first rule was applied to

the context of each of the discrete training sessions, whereas the second rule applied to the sequence of training sessions as a whole, the context of contexts. I find it important to note that the two rules were both used from the beginning but that they were not applied to contexts at the same logical level. Yet, in the experiment with the dog this was not the case. Instead, one rule was replaced by another at the end of the experiment and, more importantly, the two rules applied to contexts of the same logical type. The rule stating 'this is a context of discrimination' applies to each of the discrete training sessions in the first part of the experiment, whereas the rule saying 'this is a context for gambling' applies to each of the discrete training sessions following the change of context. The point is here that the latter context does not entail the first type of contexts as in the case of the dolphin. It simply is a new context, and as Bateson himself indicates, 'naive animals' were able to relate to the second type of context without having any notion of the first type of context. This would not have been possible in the case of the dolphin.

In terms of learning levels this process boils down to the following phases. First, the dog was trained to distinguish between two shapes, a case of Learning I, as when a dog learns to jump when being given a certain command. Next, the dog was challenged in terms of this new skill, as when the agility dog is challenged to jump over higher and higher fences when given the same command. This is a case of learning 0 in terms of information processing. And finally, a new phase of training begins where the dog is challenged to learn to gamble when being presented with two identical geometrical shapes. This phase is also a case of Learning I, but unfortunately the dog is unable to attune to this context, as it is lead to believe that it is still in the former context.

Now, Bateson states that the confusion of the dog is due to Learning II, arguing that the dog is misled by '*context markers*'. This is a surprisingly weak argument, as Learning II applies to 'contexts of context' and not just to 'context markers' – unless, of course, the notion of 'context markers' is reserved for denoting contexts of contexts. And this may be what Bateson wants to argue. When explaining Learning II, Bateson gives the example of a dog in the laboratory that gets more and more apt to operant conditioning, which is a case of 'learning to learn', and which Bateson explains in terms of the context markers of the laboratory setting – the harness, the smell of the laboratory etc. Supposedly, laboratory dogs learn to relate to a pattern of a higher logical type than each of the discrete training phases, and the context markers that Bateson talks about may denote this context of contexts. Thus, learning to see this pattern is Learning II, as a new punctuation is generated. So far so good.

However, in order to explain why the dog is confused Bateson says that it is led to believe that 'this is a context for discrimination'. This is a meta-message all right, but it is only a meta-message about the context of the first phase of the experiment, not about a context of contexts (the laboratory setting in general). Bateson (or, in fact, the dog) thus identifies the information given by the context markers with information about the specific context within the experiment. But in my view, learning to take account of such information only corresponds to Learning I. Thus, contrary to what Bateson suggests, I will argue that the experiment does not show that the behavioural disturbance of the dog had Learning II as a necessary condition.

This reasoning entails the observation that the mere fact of a context marker does not necessarily imply that Learning II has been taking place. As Bateson writes, the concept of Learning I entails the assumption that it is possible to talk about 'sameness' between two instances of a 'context'. According to Bateson: '*Without* the assumption of repeatable context (and the hypothesis that *for the organism* which we study the sequence of experience is really somehow punctuated in this manner), it would follow that all "learning" would be of one type: namely, all would be zero learning. (ibid., p. 288)' In my interpretation, this means to say that Learning I implies the concept of 'context'. In Learning I a number of 'contexts', which in many ways are numerically different, are suddenly seen as belonging to the same type of context in certain respects, or as a certain class of contexts. I will argue that these numerically different contexts in this class will entail the context marker(s) by which an organism is able to identify this type of context. A context marker saying 'this is a context of Type A' is a meta-message about that particular context. Thus, this piece of information is at a logical level that is one step above the information within that context. As explained above, learning from information within a context is Learning 0. Thus, learning to see the context as a context of a certain type is one level up, i.e., Learning I.

In my view this point about the constitution of a 'context' as something that takes place in Learning I is important in order to understand the difference between Learning I and II. I would therefore like to explain this in greater detail drawing on my example about the traffic light signals above. When encountering the traffic light signals in the foreign country I would be receiving information within the context concerning the colour of the signal. I would also draw on context markers telling me that I was being encountering 'a traffic light signal'. Hence, I would have a notion of the context in order to interpret the signal as a 'traffic light signal'. In effect, if it were red I would stop. And I would have no reason to believe that the meaning of the signal I perceived was the opposite of what I

thought. The reason is that the context markers only tell me that I should interpret the signal as a 'traffic light signal', not the way in which these traffic light signals operate. I not only need to know what context I am facing. I also need to know the rules for interpreting information within that context. And these rules I need to know from prior experience. Drawing on this I would therefore misinterpret the signal. And if I were alone in the street I would not even notice my misinterpretation. What is more, if I were not alone, instead of noticing my misinterpretation of the signal right away I would be more likely to start wondering why others would not respect the signal. If no one informed me about the traffic light system in this country I would be likely to carry on this way for some time. Eventually, my specificity of response would change concerning the interpretation of the signal. In terms of punctuation the change would arise upon a series of such incidents. I would subsume a number of events as different versions of the same context. I would thus correct my understanding of the context. My assumption about the context being a 'traffic light context' would be confirmed, but I would have to correct my knowledge about the rules applying to this context. This is Learning I in terms of 'correcting errors of choice of response alternatives'. But more importantly, this learning requires the constitution of the 'sameness' of context regarding the series of different incidents. What I want to emphasize by this example is that my knowledge about these rules cannot be updated without taking account of the context. Learning I thus requires the ability to take account of a context as a context of a certain type. Moreover, I will argue that the concept of 'context' has no meaning at learning level 0 in itself, that is, if there had never been a higher learning level from which to notice a 'difference that makes a difference' – in a certain context.

From this example it is clear that Learning I not only changes the way I learn from information within a context. What is important to notice is that this change is brought about by a change of punctuation entailing a different kind of information processing altogether. I emphasise this point in order to state that one should not identify Learning I merely with changes at Learning 0 in terms of altered ways of learning from signals. The important part would be missing, namely what made these changes possible. In effect, an organism making a breakthrough to Learning I actually changes its information processing in two different ways at the same time. It changes its way of learning from information at level 0, but it also performs a completely new kind of information processing, namely the ability to constitute a context for which this change applies. (I am not saying, of course, that the organism is aware of the 'context' as an ontological category). In terms of context markers, the organism will notice a

certain configuration of items in the environment that tells it when a certain context is present. For instance, I do not stop every time I see any kind of red light. It depends on the context. In effect, I stop if the red light is in a configuration of items that make me respond to it as a 'traffic light signal'. Likewise, a dog will notice a certain configuration of items in its environment that makes the dog interpret the behaviour of the trainer as a certain signal. This may sound like an indication of learning II. But the context markers at this level merely changes the way the dog processes information within its environment as if the dog switches to another 'register' for processing information. Before the change a sound from the trainer is nothing but a sound. After the change the sound is being perceived as a signal (for a certain behaviour). This change in itself only qualifies as Learning 0. And what made this change possible is that, at some point, due to a new punctuation of experience the dog perceived a certain context in which this certain signal had a certain meaning. In my view, this only qualifies as Learning I, as only one change of its way of punctuating events is necessary for establishing this signal.

To clarify my interpretation of Learning I and II: Learning I is the constitution of a new context 'by chance' due to a change of the way of punctuating experience. This can take place a number of times, thus constituting a number of contexts for the organism. Learning II is due to another change of punctuation, which sees a pattern in a series of such Learning I events. Thus, the organism will learn to constitute contexts, not only by chance, but on purpose – in certain circumstances it will start to look for a new context, or to explore the nature of a given context. In other words, it has 'learned to learn'. Learning II thus entails the ability to constitute and differentiate between contexts of contexts. At this level the context markers for instance make the dog able to distinguish between contexts for performance and contexts for (performing) new learning. Responding to the latter kind of context markers the dog would be more apt to constitute new contexts. It would be able to direct its Learning I. In effect, it would have learned to learn. But I do not believe that Learning II is obligatory in order to constitute a context. Otherwise, Learning I would be impossible without the capability of Learning II. Regarding the example with the frustrated dog discussed above I will point out that if the dog in fact was responding to a context marker corresponding to Learning II, then it is less likely that the dog would be stuck within in its old understanding of the actual context. Instead, due to Learning II and the ability of learning to learn the dog would have been likely to do what the dolphin did – to search for a new rule instead of sticking to the old one. In my view, contrary to what Bateson claims, Learning II would be pointing to the solution, instead of being a part of the problem.

To summarize, my interpretation of Bateson's learning theory thus emphasizes two important aspects. Firstly, it is a way of describing learning levels in terms of logical types of changes of information processing. This basic principle of description is illustrated by the experiment with the dolphin, as there were indications of a qualitative change in its way of learning to display new pieces of behaviour. This indicates a shift from Learning I to Learning II. Simply learning to display a certain piece of behaviour is Learning I. But learning to change behaviour at each performance is learning of a higher logical type. This shift is explained in terms of punctuation of context. And this explanatory principle is the second important aspect of Bateson's learning theory. With respect to this second principle, I emphasized Bateson's observation that there is a necessary relation between the notion of context and learning at higher levels than Learning 0. A change at Learning 0 simply is in terms of changes in the states of the information processing. Notably, information processing at learning level 0 may well include taking account of information at higher logical levels, as long as there are only changes in the states of the information processing. But if an organism changes its punctuation of information, its way of processing information also changes. It will be able to respond to a new *Gestalt* of information, which means to place the pieces of information that are being processed into a new context. In my traffic light example above, the set of response alternatives would be either to stop or to go, and creating a new notion of the immediate context changes the relation between sign and response. This was explained in terms of creating a new punctuation that elevated the view from merely noticing the signal (a Learning 0 event) to noticing the context (a Learning I event). Due to Learning 0 an organism operates merely in terms of information. Due to Learning I, it operates in terms of contexts of information. And as the concept of 'context' and Learning I go hand in hand, the notion of 'contexts of contexts' goes hand in hand with Learning II.

As for the concept of context markers they can function as signs for contexts at both logical levels. An organism learns to recognise a context via context markers. And once learned, an organism will be able to respond to a context via its context markers. Doing this is learning from information within the environment, which will only qualify as instances of Learning 0. But learning to do so will be a case of either Learning I or II. In the case of the dolphin, I assume that when it enters the training tank just having learned to display a new piece of behaviour at each training session, it will continue displaying new pieces of behaviour. This is Learning 0 in the sense that the dolphin simply carries on processing information in the way it has just learned (at level II) due to context markers carrying the meta-message 'this is a context for displaying new behav-

iour'. Now, let's say that the trainer at some point decides that the dolphin is no longer supposed to display new examples of behaviour. The trainer will then stop giving reinforcement when the dolphin does so. The dolphin may get annoyed and perhaps slap its tail in frustration, and the trainer will then offer a fish. This reinforcement breaks the former pattern and, thus, the dolphin may stay frustrated. Hence, it may slap its tail once again in annoyance, and get reinforcement again as it was displaying the same piece of behaviour twice. At this point it may be able to see two patterns at two different levels. First, it may understand that in this particular context it is supposed to slap its tail in order to get fish (Learning I). Next, it may notice a similarity between the actual phase of training sessions and the phase where it understood that it was supposed to change behaviour at each training session. In each case it got frustrated when being in error regarding the rules of the context, but finally it broke the code of the trainers expectations. Thus, it would see a pattern of (learning) contexts, which is yet another example of Learning II. Whereas Learning I entails the ability to observe a new context, Learning II entails the ability to observe a context for observing new contexts. What is more, its own frustration may become a context marker telling the dolphin when it is in the latter kind of context, much like 'the smell of the harness' in the case of the dog. So next time the dolphin gets frustrated during a training session this may function as a context marker that triggers the dolphin to enter the state of exploring the nature of the context. Talking about its character a trainer might say: "Well, it sometimes gets annoyed, but that only seems to stimulate its learning." The context marker thus directs its Learning I, but merely to take account of this context marker the second time would only be Learning 0, even though it has Learning II as a logical precondition.

In addition to these three learning levels (0, I, and II) Bateson discusses the possibility of Learning III and IV[11]. Following the basic principle of logical types of changing, Learning III is a change in the way of changing that characterises Learning II, whereas Learning IV is a change in the process of Learning III. According to Bateson, to demand Learning III of human beings and mammals may be pathogenic (ibid., p.293) and is rare even in human beings (ibid., p. 301), whereas Learning IV 'probably does not occur in any adult living organism on this earth' (ibid., s.293). Bateson does not discuss Learning IV at length himself, and for my purposes I will discuss only Learning III in the following. How is it different from

[11] The first version of the essay from 1964 in which Bateson presented these thoughts did not include a discussion on Learning III – this was added in 1971 (cf. Bateson 1972/ 1999, p.279). In this final version there is no discussion on Learning IV.

Learning II? In Bateson's definition, Learning III 'is a change in the process of Learning II, e.g. a corrective change in the system of sets of alternatives from which choice is made' (ibid.). What would qualify as a change in the process of Learning II? Here, one should take great care not to confuse changes at level II with changes of the process that is level II learning.

According to Bateson the outcome of a Learning II event has the potential of becoming a characteristic way of relating to the environment exactly because of the way an organism punctuates information (cf. ibid.). Above I gave the example of the dolphin that tends to contextualise itself in a learning context whenever it gets annoyed during a training session. Technically speaking, one could say that it has a tendency to punctuate its environment as a context for learning about the actual context, and that this tendency gets triggered by its own annoyance during training sessions. Now, it would be easy if Learning III were the case whenever an organism changes such traits. But there is a pitfall here, as this may be no more than a new instance of Learning II, just like a new instance of Learning I does not in itself indicate Learning II. As Bateson reported, it took fourteen training sessions before the dolphin finally made a breakthrough to Learning II and was able to put the succession of Learning I events in context. Likewise, Learning III takes a change of punctuation that puts Learning II events in context. For instance in the case of the dolphin, it would have to become aware of its own tendency to contextualise itself in Learning I contexts. Bateson states that this kind of learning is a rare event even in humans. In terms of interpersonal relations Bateson explains that the contextualisation tendencies of a person tend to reinforce themselves due to 'transference' (cf. ibid., p.249). For instance, if a person has a dependency pattern when interacting with another person, this other person will tend to take up the complementary role in order to complete the first person's contextualisation. As another example in everyday terms, a person assuming that other people are hostile will be likely to act with hostility himself, and in turn he will get hostile reactions from other people. Bateson therefore points to psychotherapy as a type of context in which such reinforcement patterns can be broken. Psychotherapy sets up a special environment where transference gets out in the open instead of working behind the back of the interacting persons. The goal on the part of the client will be to have a more flexible contextualisation pattern (cf. ibid., p.304). Learning III is not merely an exchange of, say, a dependency pattern with an independency pattern. Such strategies have to be noticed *as* strategies. Thus, a new strategy is not just replacing a prior strategy (this would merely be a new instance of Learning II). Instead of having only one contextualisation trait, the client would now have two, but

on top of that (due to Learning III) he or she would have the flexibility to shift between the two traits depending on his or her own deliberate contextualisation, as well as the ability to question existing contextualisation patterns and develop new ones.

3.3 Integrating learning levels and CHAT

3.3.1 Four levels of mediating artefacts

Marx Wartofsky's has presented a classification of artefacts in a paper from 1973, 'Perception, Representation, and the Forms of Action: Towards and Historical Epistemology' (cf. Wartofsky, 1973). In this paper Wartofsky outlines his research programme of studying the interrelation of praxis and perception. In congruence with Vygotsky, the focal principle of his historical epistemology is that perception is a form of action – or to be more precise, forms of action, which are mediated by artefacts, e.g., concepts being devised in order to handle certain elements of the 'environment', which are of interest. As a by-product of this theory Wartofsky enumerates three levels of artefacts mediating human perception. Wartofsky describes 'primary artefacts' as those being used directly in production, e.g., tools, modes of social organization, bodily skills and technical skills in the use of tools (Wartofsky, 1973, p. 201). Wartofsky's 'secondary artefacts' are representations about the productive practice concerning the primary artefacts, e.g., instructions for the use of a tool in order to achieve at certain goal.

> Such representations, then, are reflexive embodiments of forms of action or praxis, in the sense that they are symbolic externalizations or objectifications of such modes of action - 'reflections' of them, according to some convention, and therefore understood as images of such forms of action - or, if you like, pictures or models of them. [...] Secondary artefacts are [...] mimetic, not simply of the objects of an environment, which are of interest or use in this production, but of those objects as they are acted upon, or of the modes of operation or action involving such objects. (Wartofsky, 1973, p.201-2).

Finally, 'tertiary artefacts' transcend the practical concerns constraining the primary and secondary artefacts, as the original role of the representation has been 'suspended or bracketed'. In this way they constitute 'a domain in which there is a free construction in the imagination of rules and operations different from those adopted for ordinary 'this-worldly' praxis.' (Cf. Wartofsky 1973, 208-209).

As already stated, Engeström sees an analogy between Wartofsky's conceptual hierarchy on artefacts and Leontiev's concepts of activity aspects, however, without providing a detailed discussion of this analogy. He does, however, make some statements indicating how this analogy is to

be understood. Thus, he states that primary artefacts correspond to the level of operations in that 'the subject is essentially unaware of the means he or she is using' (Engeström 1990, p.173). As for the correspondence between the middle-level concepts, he points to incidents of breakdown 'when a smooth, automatic flow of operations is interrupted because of a problem, forcing the subject to enter the mode of goal-directed action and reflection on tools.' (Engeström 1990, p.173). Finally, concerning the third-level correspondence Engeström explains that 'imaginative artefacts, e.g., novel works of art, socio-political visions, scientific paradigms, religious creeds, are typically artefacts that give identity and overarching perspective to collective activity formations' (Engeström 1990, pp.173-4).

Furthermore, in 1987 Engeström conflates these two hierarchies with Bateson's learning levels, as illustrated below (Table 3.1):

Bateson 1972	**Wartofsky 1973**	**Leontiev 1978**
Learning I	primary	operation/ conditions
Learning II	secondary	action/ goal
Learning III	tertiary	activity/ motive

Table 3.1: The correspondence between three conceptual hierarchies, adapted from Engeström 1987, p.154).

Thus, in Engeström's view Learning I corresponds to the level of operations, or to be more precise, to the formation of operations when the handling of the primary artefacts is slowly being improved.

> In Bateson's Learning I, both the object/outcome and the instrument are given. Learning means repetitive corrections in the way the subject uses the instrument upon the object. There is a fixed correct way which is to be obtained. The movement is primarily one-way and non-conscious: from the object to the subject to the instrument to the object. Instruments on this level may be called tools or primary artefacts (Wartofsky 1973, 201-202 [..]). [...]Learning I is equivalent to the formation of non-conscious operations "in the course of simple adaptation to existing external conditions" (Leontiev 1981, 237). (Engeström 1987, p.143)

Notice, that in this integration of Learning I and the other primary-level concepts Engeström makes use of the concept of 'object', and in addition he states that the object is 'given', meaning that it is not consciously reflected upon by the acting subject. In Learning II, however, this is changed.

> In Learning I, the object presents itself as mere immediate resistance, not consciously separated from the subject and instrument by the learner. In Learning II, the object is conceived of as problem, demanding specific efforts. The subject is no more a non-conscious agent but an individual under constant self-assessment stemming from the success or failure of his attempts at the solution (Engeström 1987, p.149).

In Learning II the subject is no longer unaware of the object, as it is being conceived of as a problem. Engeström says that in Learning II 'the object/outcome is given and the instrument is found through trial and error [..]'. Thus, at this learning level the object is both 'a given' and being conceived of as a problem. Hence, I conclude that in Engeström's view the subject may become aware of the object, but what is in focus of the subject's attention at this learning level is not to find out about the nature of the object. What has changed is that in Learning II the instrument is in question. Hence, the subject may focus his attention on finding out what instrument will solve the problem in dealing with the object. Note, that this is similar to a breakdown situation calling for secondary artefacts. Thus, in Engeström's view Learning II corresponds to secondary artefacts and, hence, to the action level. In Engeström's account of Learning III the nature of the object is called into question, as the subject understands that his own way of relating to the object is a part of its nature.

> Whereas in Learning II the object is seen as a problem possessing its own objective dynamics outside the subject, in Learning III the object system is seen as containing the subject within it (Engeström 1987, p.151).

This learning level corresponds to what Engeström conceives of as 'true learning' or development, something that is very different from the kind of learning that has traditionally been focused on in schools (Engeström 1987, pp.95). The overall goal of Engeström's work of 1987 is to devise a set of conceptual tools for analysing such development processes in order to put them in focus. A focal part of these tools that Engeström presents is his 'expanded triangle' for illustrating the structure of activity systems (Engeström 1987, p.78). And in combination with his concept of 'contradictions' in practice he provides a series of examples of how to analyse historical accounts of personal and cultural development as learning III processes. Furthermore, in the text from 1990 he reports on an action research project in which these tools in a successful way were employed by medical practitioners in restructuring their daily practice at a malfunctioning health centre in Finland. Engeström describes that in this development process his model was being employed over several months as a Why artefact detailing structural aspects of the medical practice in order to provide theories as to why it was suffering from malfunctioning. Thus, it was

employed as a secondary artefact in a series of debates. However, concerning the development process seen as a whole Engeström concludes otherwise about the status of his model as an artefact, as he argues that such processes are 'guided with the help of artefacts that go beyond the explanatory or diagnostic 'why' function.' (Engeström 1990, p.194) Notice, that this is a nice example of a change of punctuation, indicating an upward movement in terms of learning level. Instead of being contextualised "downward" in terms of relevant What artefacts, the Why artefact was contextualised "upward" 'by creating a perspective for the future of the entire activity system.' (Engeström 1990, p.193). Instead of a Why artefact he therefore calls such models 'Where-to artefacts' as they represent 'a relatively long-term projection into the future' (Engeström 1990, p.194). In virtue of this, Engeström says about such models that '[t]heir primary psychological importance may well be their motivational power and potential for subjectification of the participating practitioners.' (Engeström 1990, p.194) He therefore claims that the Where-to artefact was functioning as a tertiary artefact in Wartofsky's sense. Notably, while he suggests that such upward contextualisation requires a new type of artefacts of which kind he wants to contribute, Engeström emphasises something else than merely climbing to the top level in the hierarchy of artefacts. The power of these top-level artefacts comes from their 'motivational powers'. It therefore follows, I will argue, that he explains their *raison d'être* in terms of the top-level concept 'activity' corresponding to the concept of 'motive'.

At this point, then, there seems to be a match between the three hierarchies. However, in 1987 Engeström suggests a correction to Bateson's Learning II. He states that when facing such situations the subject will either search the proper instrument among his familiar means through trial-and-error, or find an appropriate instrument through building a 'theory' of the problem. Engeström names these two aspects of Learning II (a) reproductive and (b) productive, respectively (Engeström 1987, p.148). In other words, the first aspect, or strategy, corresponds to finding out 'how' to deal with the problem, whereas the second strategy corresponds to knowing 'why' the new artefact will solve the problem. When introducing these sub-levels to Learning II he also introduces a minor mismatch between the hierarchies. But in 1990, without mentioning Bateson's learning levels and his interpretation of them, Engeström makes an isomorphic modification of Wartofsky's classification, as he suggests a distinction between two types of secondary artefacts. Analysing consultation work of physicians Engeström outlines a series of steps in the process of 'object formation' (Engeström 1990, pp.181-9) being mediated by various artefacts. First step in this process is the doctor's processing of the

'raw data' about the patient, i.e., the patient's external features. The outcome of this first stage is the doctor's first impressions that become the object for the next step in the process, history taking, in which the doctor develops 'a meaningful pattern'. This becomes the object of the third phase, in which a diagnosis and a treatment plan is being developed, which finally becomes the object in the fourth phase, the implementation of treatments. In this process the individual physician's actions are being influenced on the one hand by a number of rules and division of labour applying to the workflow at the health centre. On the other hand the object formation is being mediated by a number of various artefacts. In his analysis Engeström identifies three types. The first type, which he names 'What artefacts', is identifiable as external physical entities corresponding to Wartofsky's primary artefacts. Engeström notes that such artefacts function as means of identifying objects to be manipulated – 'just watch a child with a hammer in his hand, looking for objects [..]' (Engeström 1990, p.188). In the object formation process What artefacts are exemplified as data on the computer screen; as patient talk and documents; as test findings; and, finally, as medication. The next category he names 'how artefacts'. These are seen as methods and procedures that are specific to a certain work phase. From each step in the consultation work Engeström gives examples of such artefacts like 'routines of computer use', 'procedures for examination and tests', and 'instructions and algorithms behind specific therapies'. Engeström identifies this type as 'secondary artefacts' in Wartofsky's sense. However, he also points out a number of other artefacts, which the physician employs in his object formation, such as 'expectations, explanatory models of illness, hypothesis, and meaningful patterns' concerning the patient. This type he names 'why artefacts', as they explain why a certain tool will work. Engeström states that '[t]hese are too narrow and specific to be Wartofsky's tertiary artefacts – but too general to be secondary artefacts' in the original sense (Engeström 1990, pp.187-8). Nevertheless, Engeström adds them to the level of secondary artefacts. Interestingly, what is made clear in this analysis of the physician's object formation concerning the case of the patient the 'meaningful pattern' has been functioning as both 'product', 'object', and finally 'why artefact'. As the description of the Why artefacts is very close to his description of Learning IIb as 'theory response' (cf. Engeström 1987, pp.146), I find it very likely that How and Why artefacts in his view correspond to Learning IIa and Learning IIb, respectively. And as both How and Why artefacts are to be conceived of as 'secondary artefacts', this suggests that in Engeström's understanding these artefacts also correspond to the action level in terms of activity aspect. Hence, at this point, there is still a match between the first two levels of the three hierarchies, even though two of the hierarchies were expanded at the second level.

To sum up, in 1987 Engeström integrates three hierarchies in the literature concerning the concepts of activity, artefacts and learning. I find it reasonable to suggest that this integration also applies to his expanded classifications about learning and artefacts that he presents in 1987 and 1990, respectively. To further sustain this assumption, Bødker and Petersen in a paper from 2000, 'Design for learning in use', refer to Engeström's four-level hierarchy of artefacts as corresponding to a hierarchy of 'learning levels', however, without referring to Bateson (Bødker & Petersen, 2000). In conclusion, I claim that in Engeström's thinking Learning I, IIa, IIb, and III correspond to What, How, Why, and Where-to artefacts, respectively. Also, that the top and bottom level of these hierarchies are supposed to be corresponding to 'operation' and 'activity' in terms of activity levels, whereas the pair of middle level concepts correspond to 'action', as illustrated below (Table 3.2):

Learning level	**Type of artefact**	**Level of activity**
Learning I	primary What	operation
Learning IIa	secondary How	action
Learning IIb	secondary Why	action
Learning III	tertiary Where-to	activity

Table 3.2: The correspondence between concepts in Engeström 1987 and 1990, as argued above.

I do not agree on the way in which Engeström conflates these hierarchies. In the critique that follows I will begin with a focus on Engeström's use of Bateson's concept of learning levels with relation to his artefact classification. Later on, I will also look into how these findings relate to the conceptual hierarchy on activity aspects.

First of all, as also the conflation of the hierarchies shows, Learning 0 seems to be excluded from Engeström's discussion on learning levels. It is only mentioned in Engeström's quote of Bateson's definition of his hierarchy of learning levels. Recall, however, that this learning level is in play whenever an organism acquires information about its environment. Also, note that at this learning level the organism is able to draw on former instances of Learning I, as in the example where Bateson reaches for his lunch bag on his work desk upon hearing the hospital whistle from which he 'learns' that it is twelve o'clock.

> The whistle may be regarded as an answer to a question laid down in my mind by previous learning of second order [i.e., Learning I, eb[12]]; but the single event – the receiving of this piece of information – is a piece of learning, and is demonstrated to be so by the fact that having received it, I am now changed and respond in a special way to the paper bag. (Bateson 1972/1999, pp.248-9)

In my view, the hospital whistle is functioning as a primary artefact in this example. Bateson may be focusing on his work, he may be waiting impatiently for his lunch break focusing on his hunger, or he may even focus on some other artefact such as a rule stating that he is not allowed to have his lunch before noon. But since he has already learned the relation between noon and the sound of the whistle he is as likely to focus on this particular artefact, as he is likely to be reflecting on 'noon' as a phenomenon. Now, what I want to point out is that the physician in the above example given by Engeström uses the patient data on the computer screen in a similar way, namely as primary artefacts in developing the 'first impressions'. Engeström points that out too. However, contrary to what Engeström claims it follows that this way of employing artefacts corresponds to Learning 0, not Learning I. Furthermore, I claim that Learning 0 in the case of the physician would be close to the ideal. In Engeström's analysis, the physician employs both primary and two versions of secondary artefacts. If Engeström's integration of the hierarchies is true, it follows that the physician is undergoing processes of Learning I and II. But, asking a rhetorical question, what is most likely in case of a well-trained physician: Does he process the available information the same way as he has done in the past, or is he changing not only his concepts and procedures, but also his personal character every time he examines a patient? As a patient I personally would avoid the latter kind of physician, as I would take such behaviour as signs of lack of routine[13]. I would not disagree that some measure of Learning I and II is a prerequisite in maintaining a high professional standard. But the actual performance of 'a high professional standard', however, I would conceive of as Learning 0. This is a case of an important distinction between performance and changes of

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[12] As Bateson points out in a footnote, he uses a different system of numbering in this early paper being from 1959 in which this quote appears (Bateson 1972/1999, p.248).

[13] The Danish philosopher Steen Wackerhausen may disagree on this account. Ideal patient communication, he argues, has the form of a personal meeting in which the doctor courageously suspends his 'saturated concepts' (i.e., Learning 0, eb) in order to be 'touched', or even changed, as a person: '[A]t jeg tør suspendere mit "mættede forståelsesberedskab" i mødet med dig, min patient. Kommunikation er forståelse, og forståelse af dig – som et med*menneske* – kan ikke ske uden at jeg lader mig berøre, bliver rørt og måske endda selv bliver en anden.' (Wackerhausen 1997, pp.34-5)

performance as I indicated in the beginning of my presentation of Bateson.

Secondly, I do not believe that Engeström is right in his correction of Bateson's Learning II, by introducing the concepts of Learning IIa and IIb. When looking at the example he uses to explain the necessity of this distinction it appears to me that he is talking about two different learning levels in their own right. The example builds on an experiment in which young children were presented with a block-balancing task. The experimenters observed two approaches. At first, the children would have an 'action approach' in which they would simply try out a solution and measure their success by the immediate outcome. They would be happy if the blocks would be in balance, otherwise not. But after a while, the experimenters witnessed a change to another approach, which they called 'theory response' as the children would begin to make hypothetical models about the blocks and to do experiments in order to test the models.

> Within that approach, the subject does not measure his success with the immediate outcome (balanced or not balanced), but rather with the verification or falsification of his hypothetical model. If the subject has formulated the hypothesis that, put into a certain position, the block will not balance, he will rejoice when the block does not in fact balance. (Engeström 1987, p.147).

Model making in this way Engeström rightly calls Learning II. Now, in Engeström's view what precedes this 'theory response' can also be conceived of as a way of making models as 'a tacit representation or image of the way of accomplishing the tasks is necessarily generated.' What is more, Engeström also refers to this kind of model making in the 'action response' as 'secondary artefacts' in Wartofsky's terms as they are "created for the purpose of *preserving* and *transmitting* skills, in the production and use of 'primary' artefacts [...]" (Wartofsky 1973, p.201, italics in the original). He then suggests that Learning II is an oscillation between these two ways of making models as two aspects of this level of learning. 'Action response' he calls Learning IIa, whereas 'theory-response' is Learning IIb. It thus seems that his reasoning is bound to the idea that the 'action response' is a secondary artefact. In other words, it seems that Engeström employs his integration of the hierarchies in his identification of learning levels, and, in effect, in his effort to demonstrate the necessity to expand the concept of Learning II to include phenomena identified by Wartofsky's classification. But this is circular reasoning. In my view, if one sticks to the conceptual framework, which was outlined above about Bateson's learning levels, Engeström's expansion is not a necessity. Instead, it appears that the shift between 'action response' and 'theory response' is characterised by a change in punctuation. In the first phase the

child merely repeats the same context over an over in trying to balance a certain block. In the experimenting phase, however, the child relates to a context consisting of a series of different contexts, which would be characterised by various goals as sub-goals in the experiment. As Engeström points out the children were sometimes happy even when the block did not balance as this gave them some valuable information to sustain the overall goal of the experiment. This is very similar to another example that Bateson provides about trial-and-error in rats in order to illustrate the principle of logical levels of learning (cf. Bateson 1972/99, pp. 281-2). Bateson points out that a rat will not be discouraged from exploring its environment through trial-and-error even if it encounters unpleasant surprises. If, for example, a rat gets an electrical chock when looking for food, this does not tell the rat that it should stop searching this way, only that it could not find food in that location. Using trial-and-error as a strategy of getting information about the environment, getting the electrical shock is a success. And as Bateson points out, this success will not discourage the rat from future explorations of other strange objects (cf. ibid.). Bateson further explains that trial-and-error is a 'category' of behaviour, not an 'item' of behaviour. Items of behaviour can be reinforced, as when a rat learns to press a certain button in order to get food, but a category of behaviour does not follow the same laws of reinforcement. Now, Bateson does not say that this strategy is a case of Learning II in rats, and I would not suggest that either. Instead, I will point out that what he says implies that if an individual organism (not a species) were reinforced in taking up this strategy, this learning would not be at the same level as Learning I. And since it is not possible to suggest that such learning is Learning 0, it follows that it would have to be conceived of as Learning II. Furthermore, I suggest that learning to make experiments when balancing blocks belongs to the same level of learning. Learning to place a block in a certain way in order to be in balance is no more than learning an 'item' of behaviour, which is bound to that specific context. But learning to experiment is to learn a whole new 'category' of behaviour that can be introduced in many different contexts (of Learning I). Therefore, the difference between the first and second phase in the learning of the children developing the 'theory response' is not a change from Learning IIa to IIb, but merely a change from Learning I to II. Put in more general terms, it is my contention that there is no room for sub-levels at one learning level when their difference is defined in terms of logical types of changes, i.e., in terms of changes in punctuation of context.

Thirdly, I will point out that whereas Why artefacts, i.e., the 'theory response', correspond to Learning II, Engeström's How artefacts, i.e., the

'action response', correspond to Learning I. If a secondary artefact is a representation of the use of primary artefacts, then it must be a representation of what goes on in Learning 0, i.e., a routine. But a representation of something is not the same as the thing in itself. As Bateson states, to commit that kind of mistake would be an 'error of logical typing' similar to be eating the menu card instead of the dinner (cf. ibid., p.280). Hence, the representation must be at a higher logical level than what is represented. A secondary artefact as a representation of a routine must therefore correspond to Learning I. In other words, Engeström's 'how artefacts' must be corresponding to Learning I as representations of 'how' to use primary artefacts.

Fourthly, I have some reservations about a direct correspondence between Learning III and tertiary Where-to artefacts. Concerning the consumption of a tertiary artefact I suggest that it is explainable in terms of Learning II. To give an example, in Walt Disney's "Toy Story" (Lasseter, 1995) the leading character "Buzz Light-Year" gets depressed as he realises that in 'real life' he is not a 'space ranger', but merely a toy from a store. When watching the movie together with my two-year-old son both of us feel sorry for him about it. While watching this scene for the 50th time, I suddenly realised that our response was absurd. How can one feel sorry for a simple toy! However, it is as if "Buzz Light-Year" gets more real as a dramatic character by looking at the frame of reference 'outside' the movie in which a toy has no personal character. It was as if I witnessed the dynamics of my own 'suspense of disbelief' as not based on conscious decision, but instead due to a way of contextualising what was presented to my consciousness. Thus, this experience was due to a previous instance of Learning II. Like my little boy, I have learned to relate to such 'tertiary artefacts' as a play activity.

However, Engeström's Where-to artefacts may correspond to Learning III in the sense that they are employed in deliberate reflections leading to Learning III. In Engeström's view, such developmental processes can be conceived of as collective acts. While Bateson claims that Learning III is not common in individual humans, Engeström points to collectives instead. In his example of the action research project mentioned above the Where-to artefact is representing a nexus between the health workers in their individual efforts to expand their practice. This notion of Where-to artefacts is related to a major point in Engeström's thinking in that while actions may be individual, an activity system always is a collective phenomenon, and thus its transformation into a new activity system requires a collective effort. Accordingly, in Engeström's account of the physician's consultation work he only mentions What, How and Why artefacts.

Engeström does not provide an example of an individual act being mediated by a Where-to artefact.

Nevertheless, in his work from 1987 he provides an analysis, which arguably does not completely match this view of development. In the classic novel by Mark Twain (1884) Engeström finds material to test his conception of 'learning by expanding' in studying the developmental process of the main character, 'Huckleberry Finn' (Engeström 1987, pp.175). It is a story about a journey not only down the Mississippi River, and the various social classes of North America in the middle of the 19th century, but also – in Engeström's analysis – through a series of different activity systems. In trying to escape the 'slavery' of being a middle class boy, required to attend school and in many other ways being expected to adapt to a civilised way of life, Huck Finn forms partnership with two other characters, the black run-away slave 'Jim', and later on the adventurous middle-class boy 'Tom Sawyer'. Through these partnerships Huck Finn's life as a lone vagabond matures into 'joint freedom' together with Jim, and next into 'bourgeois-liberal pragmatism' together with Tom Sawyer, until, finally, he develops a completely new activity characterised by 'radical moral anarchism'. In Engeström's analysis the important thing is to show how Huck Finn through these development stages, overcomes certain 'contradictions' in his activity system by introducing new 'general instruments' in terms of new moral principles. Engeström rightly describes the first two stages as Learning II. Even though Huck Finn is changing his way of contextualising his world, Engeström emphasises that Huck Finn merely inherits the new activity systems because of the cultural impact from his surroundings. On two occasions, however, Huck Finn 'risks his neck' to save other people, something which is not explainable in terms of his former codices. On the contrary, these acts endanger his prevailing activity system. Eventually, his historically new activity emerges '*as the new actions produce richer results than expected* and thus expand, transform or even explode the constraints of the given new [the activity system inherited from Tom Sawyer, eb], turning into something wider and uncontrollable.' (Engeström 1987, p.185). At a final point, just before deciding to save Jim from slavery, Huck Finn reflects on his situation for a moment as he finds himself in 'a deadly serious moral and existential struggle' (Engeström 1987, p.183). Knowing about Jim's hiding place, he tries to 'be good' by writing a letter giving information about it to the family that held Jim as a slave. Upon completing the letter he suddenly decides to tear it to pieces:

> I studied it a minute, sort of holding my breath, and then says to myself: 'All right, then, I'll *go* to hell' (...) It was awful thoughts, and awful words, but they was said. And I let them stay said; and never

> thought no more about reforming. I shoved the whole thing out of my head; and said I would take up wickedness again, which was in my line, being brung up to it, and the other warn't. And for a starter, I would go to work and steal Jim out of slavery again; and if I could think up anything worse, I would do that, too; because as long as I was in, and in for good, I might as well go the whole hog. (Twain 1884/ 1950, 214; quoted by Engeström, 1987, pp. 183-4)

In Engeström's analysis, Huck Finn thus finds the courage to his deed by developing a new general instrument, 'radical moral anarchism'. As in a 'loss of self' (which Engeström points out is a characteristic of Learning III according to Bateson), he thus defies the bourgeois-liberal pragmatism that he inherited from Tom Sawyer. And even though he says that he is brought up to do so, Engeström argues that Huck Finn in a creative way is 'going beyond the alternatives given' by putting his actions into a whole new perspective (Engeström 1987, p.184). Engeström explains this apparent inconsistency by quoting a passage in T.S Eliot's foreword to the novel:

> Huck is passive and impassive, apparently always the victim of events; and yet, in his acceptance of his world and of what it does to him and others, he is more powerful than his world, because he is more *aware than* any other person in it. (Eliot 1950, x.; quoted by Engeström 1987, p.184)

In his discussion on this example, Engeström points out certain 'shortcomings' as he admits that 'Huck Finn is a loner and remains so', and that '[t]he case only hints at the problems and possibilities of the collective dimension in zones of proximal development' (Engeström 1987, p.192.). Thus, he acknowledges that this case is not in alignment with his principle that expansive transformation of activity systems only is possible as a collective effort depending on certain rules of exchanges and division of labour. But he states that the survival of any new activity 'becomes a question of whether or not it succeeds in creating its own social 'infrastructure': rules, community, division of labor - resulting in triangles of exchange and distribution.' (Engeström 1987, p.190)[14] Nevertheless, what

[14] Kaptelinin has pointed out that while in Leontiev's thinking activities are understood as social in the sense that they cannot be considered isolated from social relations, there is a primary focus on individual activities, i.e., activities as carried out by individuals (activities in a 'narrow sense'). In Engeström's writing, at the other hand, activities are understood solely as collective phenomena, distinguishing between individual actions and collective activities. Kaptelinin thereby identifies two main approaches within CHAT concerning the understanding of this fundamental concept, and argues that the latter distinction 'is not consistent with the general framework developed by Leontiev' (Kaptelinin, 2005). However, Kaptelinin argues that the two approaches can supplement each other.

interests me concerning the current analysis is the fact that he thereby gives an – admittedly, fictitious – example of individual Learning III[15] by way of a new 'general instrument'.

In 1987, Engeström does not call the general instrument a 'Where-to artefact', since this label was not presented before 1990. Therefore, the question is whether this label applies. If it does not apply, then in this case Learning III was not mediated by a Where-to artefact. In my view, however, Huck Finn's ultimate developmental process was mediated by a Where-to artefact. The first two 'general instruments' were helping Huck Finn in choosing between certain goals. In effect, they were functioning as Why artefacts. But when finally he deliberates on whether to inform against his friend, he creates a new general instrument in terms of the words 'All right, then, I'll go to hell' to help him decide what to do in that particular situation. This redefinition of the situation is deliberate Learning I, i.e., Learning II, much like the dolphin did. Initially, then, this also seems to be a case of a Why artefact. However, as he says the 'awful words' and 'let them stay said' he also accepts them as a new perspective for his whole existence, i.e., to refrain from reforming. This, I will argue, is a change of punctuation. In other words, he is aware that he is about to change his character. This is deliberate Learning II, i.e., Learning III. Also, I find a match between the function of Huck Finn's new general instrument and the 'Where-to' model being employed by the doctor's in their Learning III process, as it has 'psychological importance' in terms of its 'upward contextualisation' and its 'motivational power' by way of its 'projection into the future'. In my view, then, the case of 'Huck Finn' provides an example of a Where-to artefact mediating an individual Learning III process. Hence, this analysis indicates that Learning III may be mediated by a special type of artefact being tertiary Where-to artefacts.

However, this correspondence does not mean that Learning III can be identified with the employment of a Where-to artefact. I find it plausible to suggest that some people read books, go to the theatre, or go to see a psychotherapist without changing their habits of punctuation, or to be more precise, without deliberately *choosing* their habits of punctuation. As Engeström's analysis of 'Huckleberry Finn' illustrates, Learning III is associated with severe existential disturbance and a lot of courage to continue while this kind of change emerges out of otherwise groundless, or even chaotic, actions. And, in addition, as his report on the health professionals employing his model suggests, it takes many months of concen-

[15] Also, Engeström's discussion of Huck's case shows that Learning III is connected to deliberately creating a new perspective in order to handle an otherwise unbearable situation – an example of what I will later on call 'meaning-focused coping'.

trated work with the Where-to artefacts while trying to implement the new 'motivation' being represented by them. Hence, what I find illustrated by these accounts is, firstly, that while Learning III is a certain type of change, it has to be described as a process-in-action, which requires a certain amount of time – it cannot be described merely in terms of a given state of affairs at a certain point of time; secondly, that while it is mediated by an artefact, it certainly cannot be explained in terms of this artefact; thirdly, that the otherwise groundless acts are guided by a feeling of inner necessity; fourthly, that it places heavy demands on the individuals taking part in the process; and finally, that it also releases a significant amount of energy when it finally takes place.

Before moving on in my reflections regarding the relationship between the hierarchies, I would like to sum up concerning the relationship between learning levels and Engeström's classification of artefacts. Generally speaking, I value Engeström's overall idea that states that artefacts are mediating the various processes of learning. In other words, I find it of value that he tries to integrate the concepts on learning and artefacts, as opposed to Bateson who does not provide much help in analysing artefacts in learning processes. Also, I find Engeström's expansion of Wartofsky's concepts useful. Thus, I accept his alternative classification in his description of What, How, Why, and Where-to artefacts, as well as Wartofsky's concepts about primary through tertiary artefacts. However, while I agree on the relationship Engeström observes between his own artefact concepts and those of Wartofsky, I cannot agree on his view on how these artefact classifications relate to Bateson's learning levels. To recapitulate on my four comments above: First of all, I want to reintroduce Learning 0, and as I have argued, processes at this learning level are mediated by primary What artefacts. Secondly, I do not agree that it is possible to distinguish between Learning IIa and IIb as suggested by Engeström. Thirdly, in my view How and Why artefacts correspond to Learning I and II, respectively. Finally, I agree with Engeström that Where-to artefacts mediate Learning III processes. But, as he points out how such processes take up a lot of time and effort, I would like to point out that Learning III does not 'correspond' to the use of Where-to artefacts since their use does not necessarily lead to Learning III. Furthermore, I emphasise the possibility of an individual Learning III process. Hence, contrary to Engeström I am prepared to use the label of 'Where-to artefacts' on individual use of artefacts mediating Learning III processes. An over-view of my suggestions is provided by the table below (Table 3.3, next page), in which the fourth column illustrates a few examples from the above discussion.

Learning level	Type of artefact	Examples
Learning 0	primary What	data, tools
Learning I	secondary How	instructions
Learning II	secondary Why	theories
Learning III	tertiary Where-to	'general instrument'

Table 3.3: Learning levels being mediated by types of artefacts, as discussed above.

3.3.2 Four levels of reflection on activity aspects

In my critique so far I have focused on the relationship between learning levels and types of artefacts in an attempt to make my discussion less complex. In what follows I want to complete the above discussion by considering how learning levels and levels of artefacts relate to the concepts of activity levels. Basically, it is my contention that it is not meaningful to talk about a correspondence between certain aspects of activity and certain levels of the other hierarchies, at least not in any direct sense. The conceptual levels of activity denote aspects of a process, which is to be seen as a whole always representing all three aspects simultaneously. Hence, human activity can represent a particular level of learning, but learning at a particular level does not represent a particular 'level of activity'. Also, human activity can be mediated by various types of artefacts, but it is not the case that one particular type of artefact mediates only one particular aspect of activity. Nevertheless, as indicated above Engeström talks about such correspondence in vague terms. It is, however, not my primary goal to make a reading of Engeström. Instead, my goal is to clarify the relationship between the conceptual hierarchies, which I use in my analysis. Therefore, in the following discussion, based on some of Engeström's concepts, I will focus on how I find it meaningful to say that the levels correspond with one another.

Above I explained that in Engeström's view secondary artefacts 'correspond' to the action level, that is – whenever a subject is conscious about how to pursuit a certain goal he or she will employ secondary artefacts. And as Engeström says, in Wartofsky's understanding 'secondary artefacts are representations of the primary level, "reflexive embodiments of action or praxis [..]"' (Engeström 1990, p.173). Thus, secondary artefacts are connected to the idea of reflecting on the use of primary artefacts. However, there is a difference between being focused on a goal and being focused on the means to pursue the goal. When being focused on the goal the subject is certainly not being focused on the means at the same time.

And when being in need of a secondary artefact, e.g., an instruction, the subject is likely to be facing a breakdown situation, as when a 'flow of operations is interrupted because of a problem, forcing the subject to enter the mode of goal-directed action and reflection on tools' (Engeström 1990, p.173). Engeström does not use the word 'breakdown' as an analytical concept in his texts from 1987 and 1990 discussed above. However, partly with reference to this text another prominent author within the field of CHAT, Susanne Bødker, who was the first theorist within the field of HCI to study CHAT, explains the concept of breakdown situations as a key to analysing learning activity:

> Breakdowns (Winograd and Flores 1986) and focus shifts are useful for studying artifacts-in-use. Breakdowns are openings for learning, and in our unhampered daily activity, we can see some breakdowns causing a focus shift by which a use situation becomes the object of our learning activity (Engeström 1987 [..])'. (Bødker 1996, pp.149-50)

As indicated by her reference to Winograd and Flores (1986), this conception of breakdowns builds on one of the key authors within phenomenological literature, the German philosopher Martin Heidegger. In his existential analysis, Heidegger understands the active human being as being-in-the-world, as '*Dasein*', inscribing both subject and object.

> By drawing a distinction that I (the subject) perceive something else (the object), I have stepped back from the primacy of experience and understanding that operates without reflection (Winograd & Flores 1986, p.31).

In this mode of immediate experience any distinction between subject and object is artificial, a product of a certain epistemological orientation within Western philosophy that Heidegger refutes.

> The Western philosophical tradition is based on the assumption that the detached theoretical point of view is superior to the involved practical viewpoint. The scientist or philosopher who devises theories is discovering how things really are, while in everyday life we have only a clouded idea. Heidegger reverses this, insisting that we have primary access to the world through practical involvement with the ready-to-hand – the world in which we are always acting unreflectively. (Winograd & Flores 1986, p.32)

However, even if this primary access is our immediate relation to our world it is not unmediated, as it inscribes the artefacts we use in dealing with our object. As prerequisites for its '*Sorgen*', *Dasein* inscribes artefacts-in-use as 'readiness-to-hand'. Artefacts-in-use only become 'visible' as something apart from the human existence in cases of breakdown.

Heidegger's famous example is the use of a hammer in which one is focusing on the nail, not the hammer.

> To a person doing the hammering, the hammer as such does not exist. It is a part of the background of *readiness-to-hand* that is taken for granted without explicit recognition or identification as an object. It is part of the hammerer's world, but is not present any more than are the tendons of the hammerer's arm. The hammer presents itself as a hammer only when there is some kind of breaking down or *unreadiness-to-hand*. Its 'hammerness' emerges if it breaks or slips from grasp or mars the wood, or if there is a nail to be driven and the hammer cannot be found. [..] As observers, we may talk about the hammer and reflect on its properties, but for the person engaged in the thrownness of unhampered hammering, it does not exist as an entity. (Winograd and Flores 1986, p.36)

Thus, *Dasein* inscribes both artefacts and object in a way that, in my view, is similar to Wartofsky's notion of 'primary artefacts' according to which our immediate relationship to our world is always mediated[16].

My point is that when reflecting on the tools and the work processes through the secondary artefacts, the subject is not 'in action'! At least, not in action in a primary sense as *Dasein* when operating on an object while being 'essentially unaware of the means' in an 'unhampered daily activity'. Instead, the subject is in action reflecting on how to solve the problem obstructing the primary action. Secondary artefacts may function as a representation of such actions, but this is not the same as being representative of them. On the contrary, when employed in a breakdown situation they are corresponding to a state of not being in action in the primary sense. Therefore, when Engeström claims that secondary artefacts correspond to the 'action level', I conclude that this should not be understood in the primary sense of being in action.

At the same time I find his claim meaningful in a different sense. To explain how, I will take a detour through further reflections on what it means to be in action. In what follows, I will argue that actions can be described in terms of that which is in focus of a certain action, and that the levels of learning correspond to various levels of reflection on a primary action, in other words, various ways of 'being in action' while focusing

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[16] According to Winograd and Flores, Heidegger rejects the idea of mental representations as mediating our primary relationship to the world as being-in-the-world. As Wartofsky devises a hierarchy of artefacts concerning different kinds of 'representations', the parallel I see between these conceptions may be problematic. However, primary artefacts are not primarily mental representations. To put a nail in the coffin, do I use a hammer or a mental representation of it?

on a certain aspect of one's activity. To begin with, I will consider the primary level of activity, 'operations'. In accordance with Engeström, Kuutti (1996) describes the concept of operations through the interplay between 'conscious actions' and 'unconscious operations':

> Before an action is performed in the real world, it is typically planned in the consciousness using a model. The better the model the more successful the action. This phase is called *orientation*. [...] For their part, actions consist of chains of operations, which are well-defined habitual routines used as answers to conditions faced during the performing of the action. Initially each operation is a conscious action, consisting of both the orientation and execution phases, but when the corresponding model is good enough and the action has been practiced long enough, the orientation phase will phade and the action will be collapsed into an operation, which is much more fluent. [..] On the other hand, when conditions change, an operation can again "unfold" and return to the level of conscious action (so that it is not a conditioned reflex). [..] A good example of the action-operation dynamics is learning to use a manual gearbox when driving a car. At the beginning, every step in the process (ease the gas pedal, push the clutch pedal, move the gear lever to a new position, release the clutch, give more gas again) is conscious action that needs planning, sequencing, and decision [...] But soon these conscious actions begin to transform into operations; the planning and decision making will fade away, resulting in a smooth gear-changing action, far from the clumsiness of the initial attempts. Eventually this gear-changing action will also become an operation in broader corner-turning, lane-changing, and distance-maintaining actions. It will fade from consciousness. (Kuutti 1996, p.31)

There is an important difference between using these analytical tools to describe a phenomenon, which otherwise can be understood as a whole (cf. Leontiev 1978, p.67), and to use these concepts to describe a sequence of discrete phases. I will argue that Kuutti's quote above is an example of the latter. Thus, operations are 'conditioned reflexes' to be 'executed' as 'habitual routines', either triggered by the actual conditions or consciously chosen beforehand in the 'orientation phase'. Actions, at the other hand, are the conscious rehearsal of such reflexes, for example, when learning to shift gears, or it is the conscious 'planning' or 'modelling' of a performance before it actually takes place 'in the real world'. What also interests me in this quote is the choice of example, as Kuutti describes the process of changing gear when driving a car. To me this sounds as if operations denote daily 'routines' as something to be performed without thinking or, perhaps, while thinking of something else. This may be a good description of a blue-collar worker standing by the assembly line in the fashion of Taylorism. Lacking a machine to do his

work, he uses his body as a machine instead in trying to distance himself from his dull routine. I take this account as a 'blue collar myth' that explains the difference between the two concepts 'operation' and 'action', much like Leontiev's above mentioned example of primeval collective hunt illustrating the division of labour among hunters having different goals of their individual 'actions', while taking part in a common 'activity'. Hence, to me, Kuutti's quote above as well as Engeström's talk about 'automatic flow of operations' sound as if the human consciousness, residing in the brain, is somehow programming its body to perform a selection of routines. This way of describing human actions is, in my view, very similar to a cognitivistic view of human information processing, which, however, is being criticized by Kuutti himself as well as other authors within CHAT (cf. Kuutti, 1996; Kaptelinin, 1996).

Even though 'unaware operations' indisputably are a part of everyday life, are they then representative of every human performance being carried out 'in real life'? When 'operating', are we merely waiting for our body to carry out a routine in order to get on with life? Is it the case that whenever we reach proficiency in doing something, our operations will be performed 'unconsciously'? More importantly, I find this discussion relevant when describing the 'daily routines' of disease management in relation to treatment of diabetes. When speaking with theorists during my pre-investigations, it was suggested to me, that I investigate how patients find the motivation to carry out these routines. The underlying premise was that routines of this kind are seen as obstacles to living life to the fullest. Of course, I was told, the patients would be happy to get rid of these obstacles. And, of course, if they had the choice, they would. But, unfortunately, they do not due to their chronic illness. On closer investigation I found that most patients I spoke with don't think this way. Living with diabetes is a part of their identity – a part of the life they are trying to live in the best possible way. A part of their *Dasein*. Admittedly, many patients experience moments when they distance themselves from this fact, which I will examine more closely in the section of coping analysis. On the other hand, what also will be clear through this analysis is that a number of patients take great pride in maintaining their blood sugar within the correct range. One might say they are 'surfing' their diabetes, instead of being caught up in a dull routine. Similarly, Lundman (1990) described how some patients are 'experts' in controlling their metabolism by way of 'logical reasoning, factual knowledge, personal experiences, as well as objective and subjective blood glucose estimations' (cf. Lundman 1990, p.26). In describing the daily routines of patient disease management in terms of 'activity', I therefore find it necessary to reflect further on the notion of 'operations' within CHAT.

In his discussion on the general structure of human activity, it seems that Leontiev describes the concept of operation in three different ways (cf. Leontiev 1978, pp. 62-74). Firstly, concerning the realisation of human activity Leontiev distinguishes between 'actions', and 'operations' as different aspects of this process. This distinction is motivated by the observation that the goal of a subject may stay the same, while the 'methods' or 'means' by which it is achieved change if the conditions of carrying out the action change.

> For this reason, in spite of its intentional aspect (what must be achieved), the action has an operational aspect (how, by what means this can be achieved), which is determined not by the goal in itself but by the objective-object conditions of its achievement (Leontiev 1978, p.65).

Secondly, operations are described in terms of their genesis being the transformation of conscious actions into unconscious operations. Initially, an operation is an action relating to a goal that a subject is focusing on regarding a certain activity. But eventually, due to the process of technisation, the person will be able to focus on another goal, transforming the former into an intermediate result while the subject loses conscious awareness of it. Thus, the former action becomes a mere routine to be carried out automatically in a machine-like manner.

> [E]very operation [..] is the result of a transformation of action that takes place as a result of its inclusion in another action and its subsequent "technization." [..] Generally, the fate of the operation sooner or later becomes the function of the machine. (Leontiev 1978, p.66)

In this process, as the subject gets familiar with a routine, a number of isolated 'units' of activity may flow one into another. As an example, Leontiev explains that the integration of such units is to be seen in the handwriting of a child learning to copy a text. At first, the handwriting is broken up into separate letters as an indication of how the child perceives each letter as a separate unit. Later on, as the handwriting gets more fluent, this indicates how these initial units have become integrated into words or even sentences in the child's perception (Leontiev 1978, p.67). Nevertheless, as Leontiev further explains, 'before the naked eye' it is difficult to study this process of 'consolidation of units of activity and psychic reflection'. Therefore, as a third way of describing operations he points to objective indicators in measuring the physiological work of the brain.

> Among these indicators is, for example, the so-called ontokinetic nystagmus, the changing cycles of which, as investigation has shown, make it possible to determine the amount of movement

> "units" entering in the composition of graphic actions. It may be considered that such a separation, distinctly appearing on oculograms, corresponds to the division of action into the operations that make it up, which are evidently simpler and more primary (Leontiev 1978, p.67-8)

Operations, then, are described, firstly, as a certain aspect of human activity, which relates to the actual conditions of carrying out an action; secondly, in terms of technisation and machine-like behaviour; and thirdly, as a method of determining the familiarity of such routines they are described in terms of how they are stored in the brain.

Concerning the latter method of description, I have three comments. Firstly, it seems that one needs special equipment in order to analyse the 'compression' of several units of activity and their transfer to 'lower neurological levels' in order to determine what qualifies as actions and operations (cf. Leontiev 1978, p.71). However, not only is it difficult to get access to such equipment – the use of it in examining the subject is likely to interfere with what he or she is doing. Secondly, even though conscious thinking is located in the cortex, whereas 'automatisms' are located in the basic structures of the brain, releasing computational power of the cortex, and even though conscious problem solving may interfere with the 'flow' of the 'automatisms', this does not in itself entail that 'consciousness' as such should be identified with processes in the cortex, leaving out processes in the lower neurological structures. The concept of 'motive' denotes an aspect of the activity, of which the subject may not be conscious. At the same time, this concept still is relevant as a part of describing human consciousness as its driving force. In a similar way, then, the concept of operations may be regarded as an aspect of conscious processes. Thus, in my view, consciousness as a phenomenon could be described as having various features at each analytical level of activity, including the processes of the 'operations'. Thirdly, it seems that the method in question concerning the identification of operations depends on certain characteristics of the brain of the subject, instead of how the subject relates to his object. This third comment is perhaps the most important because it seems to be inconsistent with the primary principle that activities can be described in terms of how a subject relates to an object.

This leads me to a comment on the second way to describe operations. It is not the case that operations are required to carry out activities – it is the other way around: Activities are required to perform operations (cf. Leontiev 1978, p.66). Hence, in my view, to talk about operations as something in themselves as when removed from an activity changes the meaning of the word 'operation' into denoting an artefact and not an aspect of human activity. In saying this, I am aware that in Leontiev's view an op-

eration carried out by a machine still is a part of human activity in the sense that it is a part of the processes of this activity. But then he says, 'Only a "crazy" machine that has escaped from man's domination can carry out operations that do not realize any kind of goal-directed action of the subject' (Leontiev 1978, p.66). So, even though he states that the meaning of 'operation' entails a reference to human activity, even while denoting automatisms carried out by machines, he does not use the word in that sense in this latter phrase when talking about 'crazy' machines. Machines do not go 'crazy', and they do not 'escape' human activity. Such personification cannot save him from an inconsistency in using the word to denote processes that no longer have any relation to intentional behaviour. My point here is that this changes the meaning of the word in an essential way. In effect, due to this change it is possible for him to suggest that human operations are also carried out in a mindless, machine-like way. However, apart from this use of the concept, if the meaning of 'operation' is to denote an aspect of a person's activity, this suggestion is less likely. Of course, blue collar workers standing by the assembly line in the Tayloristic fashion may be supposed to emulate machines, because human thinking, according to Fredrick Taylor (1856-1915), is the source of production faults (cf. Preece 1994, p.191). Or, alternatively, workers may want to distance themselves from their dull routine this way. But since this way of operating may be a product of a certain phase in cultural history, it is not representative of human operation as such.

In summing up, I do not disagree that there are important differences in the way capabilities are located in the human brain – that conscious problem solving in the cortex may interfere with the flow of 'automatisms', and, hence, this proficiency in some respects is a matter of not having to rely on the cortex during performance. At the same time, I do not find this way of identifying operations feasible. In addition, I object to the identification of operations as 'unconscious' machine-like behaviour. Instead, I prefer the first way of describing operations in terms of how a subject in a flexible way relates to actual objective-object conditions through various 'means' and 'methods' in trying to achieve a certain goal. Thus, I want to identify operations as relating to the object in terms of the conditions for taking care of it. What is more, I consider this to be a way of displaying human consciousness. In order to break away from thinking in terms of the blue-collar myth concerning routines, I will turn to examples of craftsmanship. The underlying question is still: 'What does it mean to be in action?'

Following the blue-collar myth, a musician will delegate operations to his body through hours – or even years – of rehearsal. But this corresponds to

saying that the artist is no more than a mere listener to his own performance (of operations), which are carried out by a pre-programmed 'machine', his body. As I see it, music played in this way must is boring! The performance would not be a creative act of music making, but a mere demonstration of hours of training. Alternatively, 'the automatic flow of operations' carried out by a virtuoso is fundamentally different from automatic operations carried out by a machine. What makes the performance interesting is the musician's ability to make it an 'act', i.e., to channel consciousness into the operational aspects of music making. In his book on music and consciousness from 1987, Ind i musikken (being into music, eb), the acclaimed Danish musician Peter Bastian tries to describe musical phenomena in terms of language. Thus, he draws on the hermeneutic circle in the understanding of verbal expression, when a particular word in an utterance is understood in terms of the context (i.e., the utterance in which the word appears), while at the same time the utterance is understood in terms of the words it consists of.

> Det er indlysende, at den musikalske helhed skabes af de toner der indgår. På den anden side får den enkelte tone først sin betydning i lyset af helheden; første tone i et musikstykke forstås først, når den sidste tone klinger ud. Helheden er indeholdt i hver enkelt tone, og hver enkelt tone er overalt i helheden. (Bastian, 1988, p.111)

He therefore claims that a holistic approach is necessary when understanding a musical phenomenon, and he even describes musicianship in the same terms.

> Musikalitet er evnen til at opfatte mangfoldigheden som enhed[..] jo mere vi kan opfatte som enhed, jo mere udviklet er musikaliteten. (Bastian, 1988, p.52)

In other words, to be aware of the whole of the musical structure sets the frame of reference for concentrating on the production of the sound qualities within this structure. In music it is absurd to distinguish between the whole and its constituents, says Bastian (Bastian, 1988, p.27). Thus, I will argue that even though the musician may train his body to perform certain sequences of movements, if the musician's consciousness is about the whole, it follows that consciousness also resides in the production of sound qualities at any given moment. What the musician is not aware of, however, is which muscles to pull in order to carry out this performance, as well as all the bodily reactions being responsible for his movements. In concert with the blue-collar myth, if his consciousness interferes with these automatisms he will not be likely to keep a flow in his musical expression. And since these automatisms inscribe his musical instrument, neither is he aware of its functioning as it mediates his awareness of the sound quality. However, one thing is bodily automatisms; another thing is

the music being played, the object in terms of the actual sound qualities being produced as parts of a whole musical experience. Inspired by Bastian, I claim that the musician is trained to be aware of his music making in terms of a constant 'negotiation' with the sounds he produces, the acoustic conditions, the reactions from the audience and so on, i.e., the conditions for caring about his object being his performance of a piece of music. In my understanding, then, the musician's operational level corresponds to a way of relating to the very concrete aspects of music making. At the operational level the production of sound quality is in accordance with the conditions at any given moment, while the goal level is addressing the musical composition as a whole thereby also being a part of any given moment. This is different from understanding operations in terms of 'bodily automatisms' and as 'unconscious processes'. In this interpretation I emphasise that the two aspects do not denote discrete faculties of the brain, in which case one would have to explain how these discrete parts communicate for integration to take place. As aspects of the same phenomenon they are integrated in the first place. This follows my basic principle in this interpretation, i.e., that Leontiev's concepts denote aspects of activity in terms of how the acting subject relates to his object. My suggestion, then, is to describe a subject's operations in terms of a focus on the object in terms of the conditions for taking care of it (cf. Heidegger's concept of '*Sorge*' discussed above). Not in terms of a certain method or sequence of behaviour, and not in terms of a certain programme located in the deeper structures of the brain to be picked out by consciousness in planning an action and to be processed mindlessly. In channelling consciousness into the act of making music the musician is able to take account of the actual conditions and respond to them accordingly. As the conditions may vary from one performance to the next, what happens at the operation level will also be different.

> I Balkan-musikken improviserer vi ofte over én bestemt rytme i én toneart ad gangen, og når vi fornemmer at en anden toneart byder sig frem til dans, skifter vi simpelthen toneart. Vi bestemmer selv. Spiller vi fis-mol, har jeg et arsenal af grundmoduler og færdigvarer med hjemmefra, måske et halvt hundrede forskellige ture som kan kombineres på forskellig måde. Ofte kommer en helt frisk og ny tur ud af klarinetten, og hvis jeg kan huske den bagefter, glider den ind på hylderne til de øvrige færdigvarer. (Bastian, 1988, p.119)

Each individual performance may well be a 'flow' of proficiency in carrying out the same 'action' in terms of which goal is directing the action. A piece of music can be played in a number of different ways, and in terms of operations these variants may be very different. In this sense these variants are not the same piece of music. But in another sense, it is meaningful to say that a musical ensemble has a certain piece of music on

their repertoire, and that at in any performance they try to convey a certain interpretation of that particular composition (the goal).

> Carl Nielsens blæserkvintet har vi spillet mere en 200 gange til koncert, og selv om vi spiller de samme toner hver gang, er der alverden til forskel fra koncert til koncert. Under én opførelse fremtræder førstesatsen vital og fanden-i-voldsk, næste dag, rolig og værdig i brede strøg. Kompositionen er som en kamæleon; det er det samme dyr, men det tager farve efter omgivelserne. (Bastian, 1988, p.119-20)

Thus, while directing themselves toward the object (the actualisation of this piece of music) in terms of this goal (a certain interpretation of it being related to their understanding of their musical tradition), with the driving force of a motive (the 'urge' they feel and the reflections they have on the importance of making music), they still are able to have a 'flow' of operations, which is different from the one they had at a former performance, due to the fact that they are responding to the actual, and thus variable, conditions. Hence, such differences may not entail breakdown situations.

In breakdown situations, however, consciousness will be likely to interfere in another way. If the musician is not able to control the sound qualities being produced he will be distracted from this focus and instead begin to focus on the processes being responsible for it. Thus, due to this shift of focus the automatic 'flow' of operations will be likely to stop. I want to stress that such interference is just another version of how consciousness interferes, and not just the only one. Conscious awareness has been at play all along negotiating the flow of sound qualities being produced while taking care of the overall musical experience.

To sum up, the blue-collar myth, i.e., the understanding of operations as machine-like behaviour is familiar to a cognitivistic 'language game' in which the human being at the action level is programming its body to perform certain operations, which are then to be carried out as unconscious automatisms. Of course this can be done, as in learning by rote, but this is not an adequate description of human activity, at least not of musical performance in which learning by rote plays an important part. Instead, I claim that in proficiency the human being is able to channel consciousness into the operational level in terms of an awareness of the actual conditions for caring about the object. Hence, I claim the existence of a certain kind of conscious awareness, which, according to Kuutti, is different from planning an action in the 'orientation phase'. In my view, virtuous proficiency is distinguished from dull routine by a kind of operational awareness, which is not about the bodily operations, but is focused on the object while constantly keeping 'orientation' both in terms of the goal and the conditions for taking care of it. I would not say that the blue-collar

myth is wrong. I say only that it does not suit proficiency. Even though 'unconscious operations' may describe how a bicyclist moves his body when thinking of something else, I do not believe that Lance Armstrong would be able to win Tour de France with that kind of attitude. My point in this kind of reflection is to be more 'open' in my description of disease management 'routines'. They can be performed as 'dull routine', but they can also be instances of 'proficient care taking'.

3.3.3 Four levels of action forms

What this detour boils down to is that, in my view, it is not sensible to suggest that an artefact can be employed without being 'in action' in some way or another. Hence, it is not the case that only secondary artefacts correspond to being 'in action'. If that is what Engeström means by saying that secondary artefacts correspond to the 'action level' of activity, I cannot agree. I can agree if what is meant by such 'correspondence', is that the various types of artefacts mediate certain ways of being 'in action'. I therefore suggest that a subject may relate to his or her activity at various levels of abstraction, and that certain types of artefacts mediate these levels of reflection. Also inspired by Wartofsky, I suggest the existence of four forms of action being parts of the same activity, and that each form of action correspond to one of the four types of artefacts and learning levels. In the primary form of action the subject is not reflecting on his activity in any way. All three activity aspects are represented in this form of action, but the subject is not reflecting on them. Instead, he is focusing on the object while employing primary artefacts. When employing secondary How artefacts the subject shifts focus reflecting on the primary level of activity, the operational aspects in terms of conditions and means in order to solve a problem in the flow of primary level actions. Employing secondary Why artefacts the subject reflects on the second level of abstraction in trying to define a goal that provides a reason for a certain procedure. And finally, employing tertiary Where-to artefacts the subject may try to contextualise this goal 'upwards' by reflecting on the third level of activity that motivates the system of actions, the motive.

Once again, music making may serve as an example as to how these four forms of action relate. I will call the performance of music a primary form of action. In this form of action the musicians may use a score as a primary artefact. The musician is not focusing on the score, as the physician is not aware of the data on the screen as physical items. Instead, both are focusing on the meaning of these items with relation to a certain context, the 'object' being constituted. Arguably, the musical score is also a secondary artefact *par excellence* because it functions as a description of a routine, or a description of a piece of music in which form it is pre-

served and passed on to other musicians. I would say that it functions this way during the rehearsal phase, but not during the performance. This difference is analogue to a change of status as artefacts of the signs given by the conductor. Many times during the rehearsal phase the conductor will halt the music in order to instruct the orchestra through the use of many secondary artefacts, such as the musical score, various verbal descriptions, and gestures. In the performance phase, however, it is no longer sensible to say that the conductor 'instructs' the musicians through his signs and gestures. Or, if he does, it would be embarrassing if the audience noticed. When he instructs the orchestra they are focused on the means of performing a given piece of music; and when he conducts the orchestra they are focusing on the object, the musical performance, to preserve the flow in their musical expression. I will call the rehearsal phase a secondary form of action – it is secondary to being 'musicians' performing music. Furthermore, in his instructions the conductor may need to explain why he wants the orchestra to perform in a certain way. Thus, he may be employing Why artefacts in terms of a 'theory' of the overall make-up of the composition, the intentions of the composer, or the like. In so doing, instead of focusing on the 'means' he focuses on explaining why he has a certain 'goal' in terms of a certain interpretation of the score. Engaging in such discussions I will call a tertiary form of action. Also, the conductor may need to further motivate the orchestra in pursuit of his goal by talking about the importance of playing this particular piece of music in this particular way with respect to music as an evolving art form, its role as a social institution, and perhaps with respect to making music as an existential challenge. I find it reasonable to label such visions as 'Where-to artefacts' because he is trying to bring his 'motive' into focus in order to share it with the musicians, and to convey his urge to actualise his intent. I will call such reflections a quaternary form of action.

What I am also suggesting is that the levels of abstraction in the various forms of actions being mediated by the various types of artefacts is possible to explain in terms of a change of punctuation. In this way, Learning 0 corresponds to an initial situation of a primary unreflective form of action in which the subject is merely taking account of the relevant information in the environment. This does not correspond only to the 'operation level' in terms of relating to the conditions in the environment. All three activity aspects are necessary to describe this form of action, since the subject is also relating to the object in terms of a certain goal, or certain goals, guiding the activity, and in terms of a motive that is initiating the activity and giving it momentum as an answer to a need. As for learning level I through III, these correspond to three ways of reflecting on this primary

form of action. Whereas Learning I entails a reflection on the initial Learning 0 situation, Learning II entails a reflection on Learning I situations, as Learning III can be reached by way of a reflection on outcomes of Learning II. In Learning I, there is a change in punctuation when the subject leaps from merely noticing the actual conditions to becoming aware of the context it is facing, and then learning what must be done in such a context, much as when a dog is trained to display a certain behaviour at a given signal. Likewise, when the orchestra is taught to perform in a certain way, when given a certain sign through Learning I, it will respond to the score in a new way, when it interprets a certain 'passage' (i.e., context) in the composition, which was pointed out by the conductor. The next change in punctuation (i.e., Learning II) takes place during the rehearsal phase when the musicians have 'learned to learn' in a way that makes it easier for the conductor to instruct them. As 'musicians' in Bastian's definition, the members of the orchestra will relate to any instance of Learning I by relating to the composition as a whole, the context of contexts, in trying to grasp the vision of the conductor, which he may otherwise try to convey to them in terms of (more or less musical) Why artefacts. The final change of punctuation (i.e., Learning III) may be a rare event, or, within art, it may be what is to be expected if creating art entails a constant endeavour to reflect on the existential challenges of the human life. Table 3.4 below provides an over-view of these suggestions.

Learning level	**Type of artefact**	**Examples**	**In focus**	**Reflection on activity level**	**Form of action**
0	What	data, tools	object	(none)	primary
I	How	instructions	conditions/ means	operation	secondary
II	Why	theories	goal	action	tertiary
III	Where-to	visions	motive[17]	activity	quaternary

Table 3.4: Forms of action corresponding to various foci, levels of learning, types of artefacts, and levels of reflection on activity aspects.

[17] In table 3.4, notice the distance in terms of levels of reflection between being focused on the object and being focused on the motive. This may be problematic, since it is most common within CHAT to identify the motive of an activity with its object. However, Kaptelinin has pointed out an apparent inconsistency in Leontiev's writing concerning the conflation of these concepts (Kaptelinin, 2005). Leontiev explains that the motive only functions as excitation for the activity, while it is the goal, which gives it direction as its 'true motive'. To clarify this ambiguity, Kaptelinin thus suggest a distinction between the 'motive', which arouses, or excites, the activity, while it is the 'object', which gives it direction.

3.4 Artefact mediation, adoption and empowerment

In conclusion, I have now completed my analysis of the concepts to describe the mediation of proficient self-care. Inspired by Engeström (1987) and his conflation of three conceptual hierarchies, I have provided a critical discussion of Bateson's learning levels, Leontiev's activity aspects, and Engeström's artefact levels (derived from Wartofsky), leading to the presentation of an altered relation between these conceptual hierarchies, as well as to the combination of these concepts with a fourth set of categories concerning action forms (inspired by Wartofsky). In my discussion, I took a phenomenological approach to concepts within CHAT. First, by stressing the point that active human beings always are in action when taking care of their daily business (cf. the discussion of Heidegger's concept of *Sorge* above), however, not always focusing on primary actions. Next, by drawing on Heidegger's concept of breakdown, suggesting that learning levels apply to various levels of reflection (initiated by breakdowns in primary actions) on various activity aspects. Also, concerning the concept of primary actions, I criticised a common notion within CHAT of 'machine-like operations', while also pointing out that primary actions and operations are not the same.

The discussion on the concept of primary actions may seem quite academic. Nevertheless, it addresses an important issue concerning approaches to self-care activities, namely the difference between thinking of self-care actions in terms of 'dull routine', or – more engagingly – in terms of 'playing', or 'surfing'. I want to stress that primary behaviour does not have to be dull behaviour following a strict pattern of actions being carried out in a mind-less and inflexible manner. Primary actions can also be carried out in a more flexible way, such as an expert performance at Learning level 0. Hence, in my phenomenologically inspired approach to CHAT I have sought to interpret the concept of primary actions as wide enough to include both attitudes to everyday routines.

What follows next is that these concepts are to be used in analysing the usefulness of DiasNet to support self-care, i.e., to describe the integration of DiasNet into the diabetes patients self-care activity as well as other related artefacts reflecting certain activity aspects and, thus, certain levels of learning. This description can focus on the adoption of mediating artefacts as well as empowerment in terms of learning levels. As such, the goal of the discussion has been to a clarify concepts to be applied in a process of analysing the patient interviews in a top-down manner. To further support this appliance, I have devised a table providing three sets of examples from other domains than diabetes self-care (see appendix D).

4 Coping and DiasNet

An artefact can mediate many purposes, and in effect, have many different appearances as a tool. In this study on the usefulness of DiasNet in supporting self-care I will focus on how it mediates health behaviour of the patients, or to be more precise, how it is integrated into their health behaviour. As discussed earlier, diabetes is deeply integrated into the every day life of the patients, that is to say, an integrated part of their identity. In order to provide a systematic description of the relevant aspects of the patients' behaviour and thoughts, I have chosen to base my analysis on the concept of 'coping' as a way of describing health behaviour. In this chapter, I will first examine coping analysis from a theoretical perspective and discuss how it relates to CHAT. Next, I will discuss examples from the literature on how coping analysis applies to diabetes. Then, I will present which categories I have identified in my material. And finally, I will show how these categories are employed in analysing the integration of DiasNet into the health behaviour of the patients in relation to the double theme 'adoption' and 'empowerment'.

4.1 Coping analysis from a theoretical perspective

4.1.1 Coping ways, and coping functions

Coping has to do with how a person manages a stressful situation, i.e., an unsatisfactory life situation that the person wants to change (Lazarus 1999, p.102-3). Within Health Psychology, most studies of coping are based on the Lazarus-Folkman approach (Lazarus 1999, p.114) in which coping is defined as 'constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman 1984, p.141). In analysing coping response Lazarus & Folkman (1984) enumerates eight main 'factors' of coping: *Confrontive coping*, *distancing*, *self-controlling*, *seeking social support*, *accepting responsibility*, *escape-avoidance*, *planful problem solving*, and *positive reappraisal*. These categories were the result of a factor analysis in the development of their 'Ways of coping questionnaire' consisting of more than sixty items (Lazarus & Folkman 1984). Thus, these categories may be regarded as eight main types of coping.

Beyond these main categories of coping, Lazarus and Folkman (1984) describe coping as serving two functions, either to change the reality of the troubled person-environment relationship, or to regulate the emotional response to the problem without changing the realities of the situation. The two coping functions are called 'problem-focused coping' and 'emotion-

focused coping', respectively. Both coping functions help the person to handle a stressor. But whereas the emotion-focused coping (such as 'distancing', or 'escape-avoidance') has the effect of distancing the person from a stressful situation, the person is more actively facing up to the challenge through problem-focused coping (as in 'confrontive coping', and 'planful problem solving'). Following this line of thinking, it has been discussed whether problem-focused coping is positively related to adaption and good health, whereas emotion-focused coping is dysfunctional being negatively related to good health (Willoughby *et al.* 2000; Cosway *et al*. 2000). In relation to diabetes, an important finding is that people are likely to employ emotion-focused coping strategies such as distancing when being in circumstances that they appraise as uncontrollable (Lazarus & Folkman 1984, p.151; Park, Folkman & Bostrom 2001, p.486). As the concept of control permeates the concerns of the diabetes patient (Everett, 2001), one could therefore hypothesise that the patient will be likely to employ emotion-focused coping strategies if he or she experiences a lack of metabolic control. Thus, emotion-focused coping strategies could be associated with poor metabolic control. (I will come back to this hypothesis in the literature review on coping in diabetes). In Lazarus and Folkman's view, however, this account would be too simplistic. Firstly, the two functions are not to be conceived of as a dichotomy, or as discrete action types, which is one of the main misinterpretations of the Lazarus-Folkman approach (Lazarus 1999, p.123). Most ways of coping serve both functions supporting each other, as when a student facing an important exam takes a diazepam pill in order to handle a distressing and disabling level of test anxiety. Next, due to the complexity of most stressful situations most people employ a large number of the coping factors mentioned above. Furthermore, emotion-focused coping is more appropriate as a response to the threat of complications, which it is beyond the ability of the patient to affect directly (Lazarus 1999, p.124; Folkman, 2001). Also, in case of a controllable disease like diabetes the emotion-focused coping strategy 'acceptance' can be essential for a patient to take proper care of the disease. As anger might be directed towards diabetes, thus being a hindrance for a patient to care for his or her illness, taking care of these emotions might be essential for self-care (American Diabetes Association, 2006). In addition, I will claim that not all instances of problem-focused coping are advantageous. Problem-focused coping can be so short-sighted that it is dubious whether the motivation is to confront the problem, or if the primary function is to push the problem away in a way that is similar to the distancing effect of emotion-focused coping.

Originally, the two basic coping functions were pointed out by Folkman in her dissertation from 1980. They keep being discussed as the basic functions in a recent book by Lazarus (cf. Lazarus 1999, p.114). However, in 1997, Folkman suggests a third function, meaning orientated coping, which is neither focused on changing the realities, nor the emotional response to these realities of the stressful situation (cf. Folkman, 2001). Instead, it is focused on changing the way the subject relates to the problem. For instance, care-taking relatives to seriously ill patients may begin to value days with only little suffering, or they may alter their life values completely (Park, Folkman & Bostrom, 2001). It thus resembles 'positive reappraisal' being one of the factors pointed out by Lazarus & Folkman (1984).

4.1.2 The dynamics of coping: Appraisal, process, and structure

The core of the Lazarus-Folkman definition is the concept of appraisal, which has to do with the way a person construes the relational meaning of a situation in terms of its significance for his or her well-being (Lazarus, 1999, p.9). This relational meaning is shaped by actual conditions in the environment, such as demands, constraints, opportunity, culture, and by personal variables, such as goal commitments, situational intentions, beliefs about self and world, personal resources, and values (cf. Lazarus, 1999, pp.60; Lazarus & Folkman, 1984, p.63). However, the relational meaning is not merely a product of an 'interaction' between these two sets of variables. Instead, it is a personal construct from an adaptational 'transaction' in which the person relates to these two sets of variables in terms of the personal implications of what is happening (cf. Lazarus 1999, p.13). There are two kinds of appraising: What is at stake? And what can I do about it? Primary appraising asks the fundamental question whether the environmental conditions endanger the personal variables as listed above, of which the person's goal commitment is the most important factor (Lazarus 1999, pp. 75-6). Secondary appraising is an evaluation of coping options, which has consequences not only for the emotional outcome of the stressful encounter (Lazarus 1999, pp.93), but also the choice of coping.

> When conditions of stress are appraised as changeable – that is, they are viewed as falling within the person's control – problem-focused coping predominates. However, when the conditions are appraised as unchangeable, emotion-focused coping predominates (Lazarus 1999, p.121).

As a concept secondary appraising does not denote coping in itself, but the cognitive underpinnings of coping. However, in real life it may be part of an active search for information in which case it is part of the cop-

ing process (Lazarus 1999, p.76). In a concrete situation, then, it may be difficult to distinguish between appraising and coping. However, the important point is that the concept of coping analytically is founded on the concept of appraising denoting an evaluative process through which a person cognitively construes a relational meaning of the environmental conditions.

In this way, the concept of coping in the Lazarus-Folkman definition is tied to a 'process approach' as opposed to a 'structure approach' (Lazarus & Folkman 1984). A structure approach would study coping as personal traits, such as habits, without taking account of the concrete situations in which such coping traits come into play. This ignores the situational motivation of the subject and thereby simplifies the intrapersonal variability from one situation to the next (Lazarus 1999, p.108). In contrast, the process approach is looking into how a relational meaning is construed from the environmental conditions of a concrete situation. Also, the process-oriented accounts of coping do not include reports on what a person *might* or *would* do (Lazarus & Folkman 1984, p.317). Instead, it details how a person thinks, feels and acts in a stressful situation through the various stages of coping as this particular situation unfolds. As advised by Lazarus and Folkman, 'We must identify the multiple demands in a stressful transaction and assess coping with respect to those demands and how they shift over time.' (Lazarus & Folkman 1984, s.317). Hence, when studying coping processes one must ask very specific questions about the concerns of a subject, as, e.g., coping with cancer has all kinds of aspects: The pain, insecurity, one's relatives, the doctors, economy, future perspectives, and so forth.

In his recent review of coping research since 1984, Lazarus finds that the Lazarus-Folkman approach has been dominating in most fields including coping with various kinds of illnesses (Lazarus 1999, p.114). At the other hand, this process approach has been criticised and opposed by other researchers who tended to take a trait approach looking for coping-styles (cf. Cosway, Endler, Sadler, & Deary, 2000). According to this approach, coping-styles can be seen as a psychoanalytic concept as a part of a person's unconscious mechanisms of ego-defence. In favour of this approach, Cosway *et al.* (ibid.) reports from a quantitative study based on responses from 730 Scottish consultant doctors and farmers in which they found a positive relationship between emotion-oriented coping and neuroticism, and a negative relationship between task-oriented coping and neuroticism. In addition, it seems that the process approach is difficult to apply in studying coping with a chronic illness like diabetes. As the process-oriented approach defines coping as 'constantly changing' it does not include automatized adaptive behaviour or routine efforts by definition

(Lazarus & Folkman 1984, p.131). But as pointed out by Lundman (1990) routines take up a considerable part of how diabetes patients manage their disease.

While not commenting on the problems concerning chronic diseases, Lazarus has recently commented on the drawbacks of the process approach saying that it runs the risk of being too contextual, while not taking account of interindividual differences.

> The major limitation of the process approach is anything but trivial. It runs the danger of being too contextual at the expense of the big picture, the overall, coordinated coping strategies a person employs in dealing with life, the personality variables that produce this coordination, life goals and outlooks that make a person go forward in a steady adaptational direction, at least for a time, rather than merely reacting passively to the momentary pressures of the immediate conditions.' (Lazarus 1999, s.117)

He therefore now favours a third approach which is open to taking account of certain personal traits influencing the process of appraising. Lazarus calls it a 'conditional trait approach', in which 'certain environmental conditions are said to be made *functionally equivalent* by a trait, such as a goal commitment or belief' (Lazarus 1999, p.104). Hence, this third alternative is a combination of the other two approaches while still being founded on the concept of appraisal and the construction of relational meaning as a situation specific process.

In my view, this correction of the process approach makes it possible to include disease management routines as part of coping if such routines are employed as the result of an appraising of situation specific conditions, which are made 'functionally equivalent' with relation to a certain goal commitment.

4.1.3 Cognitive mediation and the congruence of coping theory and CHAT

The theoretical underpinnings of the Lazarus-Folkman approach to coping is cognitive mediation (Lazarus 1999). This explains why coping in their theory is based on the concept of appraisal. As a theoretical approach within psychology cognitive mediation is in opposition to behaviourism, which was the prominent approach when Lazarus began his research in the middle of the 20th century (Lazarus 1999, p.5). As mentioned earlier, the concept of cognitive mediation is also foundational within cultural historical psychology. Hence, concerning this basic feature, coping theory is compatible with the school of CHAT. In addition, other similarities are found in the way Lazarus and Folkman emphasise the concept of a subject's 'relational meaning' as a transactional process,

as well as in the prominence of studying concrete contexts in these terms is in congruence with the CHAT approach. At a lower level of abstraction, another essential similarity is illustrated by the following quote in which Lazarus talks about the onset of stress:

> The person goes about attending to routine matters until there is an indication that something of greater adaptational importance is occurring, in which case it will interrupt the routine because of its potential for harm/loss, threat, or challenge. (Lazarus 1999, p.76)

This way of describing the onset of stress is, in my view, close to the way breakdown situations were described above. Both concepts are described in terms of environmental conditions obstructing the attainment of a goal commitment. Furthermore, in Lazarus' further development of his process approach, his formulations of a 'third approach' studying traits in terms of 'functionally equivalent conditions' seems to be in harmony with analysing how a person is orienting himself in terms of a 'motive'. The concept of 'functionally equivalent conditions' is explaining certain traits of how a subject copes in breakdown situations. Likewise, as the concept of motive is denoting a subject's driving force it may function as an explanation of certain traits in the way a subject is orienting himself in his environment and sets goals.

Therefore, in my view, the two approaches may be integrated by viewing coping processes as an integrated part of human activity as studied within the school of CHAT. Whereas coping theory provides a detailed analysis of how a stress response unfolds in a breakdown situation, CHAT is more detailed in its analysis concerning how the goal commitment is established, and how a motive functions as a driving force. Thus, instead of merely talking about 'attending to routine matters' as Lazarus says in the above quote, the CHAT approach may provide a deeper analysis of the background of coping processes, not only in terms of processes of appraisal when a breakdown situation occurs, but also in terms of 'unhampered' daily activity (cf. the above quoted passage from Bødker 1996). In addition, as opposed to coping theory, CHAT is much more concerned with artefacts and how tools and skills are internalised in human activity. In contrast, it seems that the concept of artefacts is missing in the list of personality and environmental variables influencing the process of appraisal as discussed above. In particular, the 'personal resources' are described in terms of 'intelligence, education, money, social skills, a supportive family and friends, physical attractiveness, health and energy, and favourable ways of thinking, such as optimism' (Lazarus 99, p.104). No artefacts mentioned. However, concerning the process of appraisal Lazarus and Folkman states:

> Regardless of its source, any shift on the person-environment relationship will lead to a reevaluation of what is happening, its significance, and what can be done. (Lazarus & Folkman 1984, s.143)

Hence, by integrating coping theory with CHAT, it is my goal to analyse how a certain set of artefacts mediate health activity in diabetes patients in terms of coping. The concept of coping is thus employed in order to identify the most relevant situations in health activity. But first, in order to qualify the coping analysis of my material, I will take a look at how coping has been studied in diabetes.

4.2 Coping in adult patients with Type 1 diabetes

Within coping research the relation between health and coping is a growing field (Lazarus 1999, pp.118; Folkman 2001), as also the relation between adherence and coping seems important (Folkman 2001). Nevertheless, even though diabetes is a controllable disease to a large extent, and coping is consequently relevant, only a few studies have focused specifically on coping among adults with Type 1 diabetes (Karlsen & Bru, 2002). In what follows I will report on a few studies that I find relevant for my purpose primarily focusing on studies in adults suffering from type 1 diabetes. Being interested in coping as a way of analysing health behaviour, it is not my goal to provide a comprehensive literature review on findings concerning coping as a health indicator within diabetes. Instead, my goal is more modest, to provide a background for my own analysis in terms of an account of the diabetes specific coping strategies that inspired me while analysing my own data.

In a qualitative study from 1990, Berit Lundman was looking into daily living and coping of 20 IDDM subjects in Sweden. Focusing on adult IIDM patients, Lundman's aim was to develop a model for diagnostic reasoning in nursing not only taking into consideration how pathology affects the patient's daily life, but also the influence of the patient's resources, habits and coping abilities, and how these factors affect emotional and physiological outcome (cf. Lundman 1990, pp.17, and p.34). Being inspired by the Lazarus-Folkman approach, she organised her findings on coping strategies into two categories, emotion-focused and problem-focused coping strategies (Lundman 1990, p.101). Next, by looking for the most prominent strategy for each individual, Lundman found a number of different patterns, or blends, of coping strategies (Lundman 1990, p.97). Here, she identified a number of coping strategies, which she organised into five different sets or profiles: *Active routinization, passive routinization, emotion-based action, ambiguity,* and *expertise*. When looking into the relation between these profiles and emotional well-being as well as metabolic outcome Lundman found that the winning strategy,

the 'expertise' profile, was characterised by a large representation of problem-focused coping and a minimum of emotion-focused coping (HbA_{1c} = 7.0%, six subjects, 0.4 sd). In contrast, she found that the profile 'emotion-based action' was associated with the worst metabolic outcome (HbA_{1c} = 9.8%, five subjects, 0.1 sd.). This profile was characterised by heavy use of emotion-focused coping, but it was also associated with a number of problem-focused strategies, such as 'subjective estimation of blood glucose', 'no regular objective estimation of blood glucose', 'reasoning based on emotions'. Interestingly, the 'emotion-based action' profile was also related with a high degree of emotional well-being. In contrast, the patients having the 'active routinizers' profile were much better stabilised compared to the patients having the pattern of emotion-based action (HbA_{1c} = 7.3; 1.6 sd; 2 subjects). This profile was characterised by only a few problem-focused coping strategies ('routinization'; 'objective blood glucose estimation'), and also few emotion-focused ('acceptance', 'deliberate temporal distancing'). However, they felt much worse. This finding relates to another part of her study, in which Lundman found an association between tedium and very good metabolic control. She speculates that, 'Perhaps the price for good control is, in many patients, exhaustion caused by too high an ambition' (Lundman 1990, p.72). She further observes that as it has a negative effect on the general well-being in terms of emotional outcome, it may prove to be counterproductive in the long run in terms of metabolic control. Thus, she concludes that 'The overall objective in good diabetes care cannot therefore be defined only in metabolic terms' (Lundman 1990, p.73). Instead, as it is important to view the disease as only a part of the patient's total life, both metabolic and emotional outcomes have to be addressed (Lundman 1990, p.109). Her advice therefore is that planning of nursing interventions should include considerations of the unique set of coping strategies of the patient (Lundman 1990, p.109).

Similar observations are found in a quantitative study (Bott *et al*., 1997) looking into the metabolic control in 636 type 1 diabetes patients responding to a questionnaire, of which one of its sub-scales, taken from the ATT39 test, was concerning (emotional) coping. The research team found the predictive value of the coping scale to be in accordance with previous findings from the same team (Bott *et al*., 1994), indicating that active coping strategies, perceptions of self-efficacy and social support are closely associated with favourable metabolic control.

In a recent explorative study from Norway, Karlsen & Bru (2002) looked into coping styles in adults with type 1 and type 2 diabetes to study the differences between these groups. This was a quantitative study collecting data from over 500 subjects by way of a questionnaire mainly consisting

of the sub-scales from Diabetes Coping Measure, to which they added a few sub-scales from COPE, and one sub-scale from Lazarus & Folkman's (1984) The Ways of Coping Questionnaire (cf. Karlsen & Bru, 2002). Through an explorative factor analysis the following eight factors were identified: *Seeking social support*, *Integration*, *Denial/ mental disengagement*, *Seeking knowledge*, *Resignation*, *Planning*, *Self-blame*, and *Tackling spirit*[18]. As this study was looking for coping styles it is not in complete alignment with the Lazarus-Folkman approach. Instead, the concept of coping styles refers to Carver (1989). Carver, however, operates with the fundamental distinction between emotion-focused and problem-focused coping, which is also fundamental in the discussion by Karlsen & Bru (2002), as they distinguish between active, task-oriented coping and passive, emotion-focused coping. On the one hand, they report that active, problem-focused coping strategies were seldom employed. Firstly, 'every second reported seldom seeking knowledge, whereas one in three reported seldom planning or being systematic in their approach to diabetes-related problems'. Secondly, as the factor 'Integration' was heavily represented among the respondents, the authors point out that 'our results [..] indicated no significant associations of integration with active coping styles'. On the other hand, their study shows that 'only a small minority of the respondents seemed to respond to diabetes-related problems by passive, emotional-focused coping such as "denial/ mental disengagement" and "resignation"'. However, a substantial proportion of the respondents reported that they often blamed themselves. Interestingly, they found a significant association between self-blame and some active coping styles as well as some passive, emotional coping styles. Their explanation is that active coping may stimulate self-blame. Concerning the comparison of coping-styles among type 1 and type 2 patients, the coping-style 'seeking social support' represented the main difference between these groups as it was more often employed in type 1 patients. Due to the factor analysis, this factor comprises both 'seeking social support for instrumental reasons' and 'seeking social support for emotional reasons', of which the first strategy is regarded as problem-focused coping,

[18] Concerning this list of factors I find it necessary to explain the meaning of two of them. 'Tackling spirit' may be equivalent to wishful thinking as this sub-scale consists of the question: '*I believe that research will discover a cure for diabetes before long*'. Examples of questions concerning the 'Integration' factor are: '*Having diabetes over a long time changes your outlook on life for the worse*'; '*I think it is unfair that I should have diabetes when other people are so healthy*'; '*Diabetes makes me feel different from everyone else*'. Hence, this factor perhaps can be described as a measurement to what degree patients feel impeded by having diabetes as a part of their life, and to what degree they have accepted the fact that they have diabetes as being a part of their identity.

whereas the other is conceived of as an emotion-focused strategy. In general, however, this factor was not heavily represented, as about two-thirds of the subjects in the total sample reported 'seldom' or 'very seldom' seeking social support. Karlsen & Bru (2002) conclude that while their study on the one hand indicates an ample potential to improve active, task-oriented coping styles through training, at the other hand it also indicates the dilemma that such training may stimulate self-blame, which may increase the risk of tedium.

Another recent study by Seiffge-Krenke *et al*. (2003) was also quantitatively and exploratively looking into coping-styles in type 1 patients, while having a longitudinal design studying 98 patients for four years. Even though this study is focusing on adolescents, I include this study in this review as it is not focusing on coping related to the onset of diabetes as a critical life-event, or coping related to invasive medical procedures, like the majority of studies looking into coping in adolescents (Seiffge-Krenke et al., 2003). Instead, it is interestingly looking into the impact of non-illness specific everyday stress on metabolic outcome. While referring to a work by Lazarus and Launier in their definition of coping, this study does not seem to be close to the transactional approach. Instead, it appears to be heavily focused on coping as a trait, as they are trying to establish a relation between medical adaptation and the coping-styles of young people being faced with everyday, non-illness related problems concerning self, parents, peers, opposite sex, school, leisure time, vocational goals, and future. In an earlier study from 1995, Seiffge-Krenke found the following three coping styles in adolescents: *active coping* (e.g., "I discuss the problem with my parents"), *internal coping* (e.g., "I think about the problem and try to find different solutions"), and *withdrawal*, a form of avoidant coping (e.g., "I withdraw because I cannot change anything anyway"; cf. Seiffge-Krenke *et al*., 2003). In the present study (Seiffge-Krenke *et al*., 2003) it was found that adolescents having HbA_{1C} scores below 7.6 also employed less avoidant coping in dealing with minor stressors, compared with other patients in the sample. Hence, they conclude that in adolescents 'medical adaptation is indeed linked to psychosocial adaptation'.

Another recent quantitative study from Japan (Nomura *et al.*, 2000) was also looking into the relation between HbA_{1C} and coping in 153 diabetes mellitus patients by employing a Japanese version of the Jalowiec and Power's coping scale. This coping scale is a non-diabetes specific coping scale for American patients with various chronic illnesses. In analysing the responses, the 40 items of the scale was divided into two categories, problem-oriented and emotion-oriented coping, referring to these as 'types' of coping with reference to Lazarus & Folkman. Furthermore,

they divided the sample into two groups concerning metabolic control. Surprisingly, they found that the proportion of patients employing problem-focused coping was higher in patients with poor control (having HbA_{1C} higher than 7.0%) than in patients with good control. However, as this study was not explorative like the other quantitative studies discussed above, it does not add to the understanding of coping types among patients with type 1 diabetes. Furthermore, while their simple division of the items into two antagonistic 'types' of coping is not un-problematic in itself, especially as they are referring to Lazarus & Folkman, the way these two categories are applied to the items is also questionable. The following items '*Accept the situation as it is*', '*Try to find meaning in the situation*', '*Settle for the next best thing*', '*Talk the problem over with someone who has been in the same type of situation*', '*Do anything just to do something*', and '*Let someone else solve the problem*' are all regarded as instances of problem-focused coping, while in my view it is easy to think of situations in which such strategies could serve an emotion-focused function as well. At the other hand, the item '*Meditation; yoga; biofeedback*' is regarded as emotion-focused coping in this study, while in my view this strategy could also be conceived of as problem-focused coping.

Other approaches to coping have also been studied in diabetes research, such as the concept of 'locus of control' (Gillibrand & Flynn, 2001) and 'sense of coherence' (Lundman & Norberg, 1990; Lundman, 1993; Richardson, 2001; Bergström & Wahlgren, 1997). The latter approach builds on the work by A. Antonovsky (1987), according to which coping ability and experience of health are connected to the degree of 'sense of coherence', i.e., to what extent stress situations are experienced as manageable and meaningful (cf. Lundman, 1993). Concerning 'locus of control' this concept can be traced back to J.B Rotter's social learning theory from the 1950'ies and is employed in order to monitor factors influencing self-management behavior in terms of internal control, external control, and influence of powerful others (cf. Shaw, 1999, p.1250). As the 'locus of control' concept denotes factors having influence on the coping process in terms of secondary appraisal, i.e., appraisal of coping resources (cf. Shaw, 1999, p.1247), while not denoting actual coping behavior, I have not included such studies in my review. Also, I have excluded studies of the 'sense of coherence' approach due to the same reason.

In summary, none of the studies included in this review (Lundman, 1990; Bott *et al.*, 1997; Nomura *et al.*, 2000; Karlsen & Bru, 2002; Seiffge-Krenke *et al.*, 2003) seem to be in alignment with the transactional Lazarus-Folkman approach (Lazarus & Folkman, 1984). Instead, all of the studies were focusing on coping styles. And while most of the studies were explorative, only one of the studies had a qualitative and narrative

approach to eliciting information from the subjects (Lundman, 1990). Nevertheless, all of the studies were heavily influenced by the Lazarus-Folkman approach in other ways. Thus, most of the coping strategies were categorised in terms of a fundamental distinction between external, active, problem-focused, and task-oriented coping on the one hand, and internal, passive, emotion-focused, and distancing coping on the other hand. A number of coping strategies, however, proved difficult to categorise this way, including '*seeking social support*', '*avoidant coping*', '*routinization*' (both active and passive), and '*integration*', while '*acceptance*' in one study was categorised as problem-focused coping (Normura *et al*., 2000). Furthermore, in my view some forms of emotion-focused coping may qualify as active coping, such as '*deliberate temporal distancing*'. And while Nomura *et al*. (2000) regard the coping strategy '*Do anything just to do something*' as problem-focused coping, I will argue that it may also be serving a distancing coping function as well. This particular example may be regarded to be in favour of the Lazarus-Folkman's process-approach, because one has to look into the coping process in more detail in order to evaluate to what extend the basic coping functions are represented.

More in alignment with the trait approach, four of the studies were looking into the relationship between coping styles and metabolic control (Lundman, 1990; Bott *et al.*, 1997; Nomura *et al.*, 2000; Seiffge-Krenke *et al.*, 2003). It was found that good metabolic control is associated with less avoidant, active task-oriented coping (Lundman, 1990; Bott, 1997; Seiffge-Krenke, 2003), active routine-based coping (Lundman, 1990), and some emotion-oriented coping strategies, e.g., deliberate temporal distancing (Lundman, 1990), while passive, emotion-oriented coping as a pattern is associated with poor control (Lundman, 1990; Bott, 1997; Seiffge-Krenke, 2003). Hence, these studies support the hypothesis discussed earlier, saying that patients experiencing a lack of control will be likely to employ emotion-focused coping strategies. As a 'dark swan' in this picture, one study found that poor control is associated with problem-focused coping (Nomura *et al.*, 2000). While this may seem plausible, as patients with poor control may experience more problems to deal with as opposed to well-stabilised patients, I have indicated some reservations concerning the findings in that particular study. Concerning the relevance of such knowledge in diabetes care, it is found useful in terms of coping training and of personalising treatment according to a patient's coping styles. At the same time, however, it was also pointed out that teaching active coping styles might lead to tedium, which may be an impediment to functional coping in the long run (Lundman, 1990; Karlsen & Bru, 2002).

4.3 Coding for coping and clarifying concepts

4.3.1 Coding for coping strategies related to diabetes

Employing a CAQDAS (Computer Assisted Qualitative Data Analysis Software) PC-application, NVIVO 2.0, the transcripts were analysed together with my notes, to identify data concerning coping in the nine patient interviews. In this study, coping means *a diabetes patient's own internal or external actions in order to manage an appraised problem concerning disease management*. This coping definition is mainly inspired by the Lazarus-Folkman approach. As applied to this study, it is important to note that the kind of actions in question is:

- Initiated by a diabetes patient's appraisal of a certain state of affairs, or signs of the development of such a state of affairs, as being dangerous or unpleasant; hence, since this study is concerned with coping with a chronic disease, I intend to include disease management routines as coping actions even in cases where a patient does not experience a stressful situation; this extension of the process-oriented Lazarus-Folkman definition of coping (1984) is inspired by the 'third approach' suggested by Lazarus (1999), as discussed above, according to which 'certain environmental conditions are said to be made *functionally equivalent* by a trait, such as a goal commitment or belief'; thus, in my understanding of this approach, coping not only applies to actions when experiencing a stressful situation, but also to actions as a response to a certain state of affairs in order to diminish an appraised risk of, e.g., a hypoglycaemia, late complications, and so forth;
- concerned with the management of diabetes related problems (i.e., lack of metabolic control), which – in this study – does not include late complications as such, but indeed relates to dealing with a lack of metabolic control increasing the risk of developing late complications;
- a patient's own, actual actions, not the doctor's or any other care taker's, and not merely potential actions, e.g., as planned in wishful thinking, while never actually being carried out in real life; regarding the latter comment, wishful thinking concerning potential self-care indeed counts as coping – however, in that case the action to be coded as coping is not the potential actions, but the wishful thinking about them;
- complex and situation specific processes, which – in this study – are to be analysed in terms of their constituents as various 'types of

coping strategies' in order to study how DiasNet and related artefacts support such actions.

To begin with, I coded passages containing what I considered to be cases of coping, e.g., a patient's account of a stressful situation, or a response to one of my questions concerning such episodes. But since I wanted to describe the various coping actions as detailed as possible, the next step was to take a closer look at particular passages containing a 'story' about a coping process and to analyse the various instances of coping behaviour that it consisted of. This way, one instance of coping could represent many different instances of coping behaviour. Hence, sometimes a particular string of characters was coded as more than one type of coping behaviour. Using open coding procedures I avoided applying coping concepts from the literature. Instead, I labelled a given passage by a short description being delimited by the small number of characters that NVIVO 2.0 allows for labelling. The resulting small chunks of labelled text each representing a specific piece of coping behaviour then became my 'data' in terms of specific 'coping strategies' being employed by the patients in various occasions of coping.

The next step was to group these coping strategies in order to identify main categories. Reading and re-reading the transcripts to become familiar with the data allowed similarities in the data to be recognized. Employing this bottom-up strategy a number of categories and sub-categories emerged, as I experimented with various ways of grouping the coping strategies. As the coding process was undertaken using NVIVO 2.0 it was quite easy to experiment with various ways of grouping the coping strategies, or to change a label of a given group.

At the same time, a top-down approach was also employed as an attempt to apply some of the coping concepts from the literature. Especially, I found a lot of prototypical examples of problem-focused and emotion-focused coping strategies, and I also found it appropriate to apply the concept of meaning-oriented coping (which I will call 'meaning-focused coping'). In addition, I found a lot of examples of routine behaviour. I decided to include these as 'routine-focused coping strategies', but unlike Lundman, I did not distinguish between an active and passive mode.

A large number of the coping strategies, however, were difficult to categorise either way, as more than one of the known categories were applicable. At this point, I found that I could either choose to label a given coping strategy by more than one category, or I could take up the challenge to analyse which category was the most appropriate. I decided on the latter alternative in order to clarify my understanding of the concepts. The process went on in cycles of categorising the coping strategies, work-

ing on clarifying the concepts, and then going back to edit the categorisation once again, and so on. In an attempt to validate my coding, two professional psychotherapists (cf. the preface) were consulted throughout the coding process to comment on the labelling in specific cases. Also, my choice of label in any given case was influenced by the larger context, being the patient interview and my knowledge about that particular patient.

It is difficult to report from this process in detail. It is much easier to only present the end result. However, I fear that a mere systematic description would make it seem as if a top-down approach predominated in the coding procedure, which was not the case. In the following account of the coping concepts I developed, I have tried to give an account of the process of categorising the coping strategies, in order for the reader to have as much insight as possible in my dispositions during the process of developing the categories.

4.3.2 Coping functions

At some point during the experimental work of categorising the coping strategies, I felt that the editing process not only had a cyclic character, but that I sometimes kept moving the same coping strategies back and forth between different categories. I therefore decided that I needed to device a method to ensure progression in this process. Instead of choosing between a number of various coping concepts, the idea was to make a certain primary decision when categorising a particular coping strategy. Here, I was inspired by the Lazarus-Folkman approach and the distinction between emotion-focused and problem-focused coping as two fundamental coping functions. Lazarus & Folkman state that this distinction is not to be conceived of as a dichotomy between discrete action types, as most coping behaviour is serving both functions. Nevertheless, I felt that it was meaningful to operate with a dichotomy concerning coping function, yet, I avoided employing the concepts of emotion-focused and problem-focused coping to do so. As also suggested in a previous work (Boisen et al., 2003), some instances of problem-focused coping can be so short-sighted that it is dubious whether it stems from a motivation to actually confront the problem and to find a durable solution, or merely to push the problem away. For instance, in case of running a high blood sugar level a diabetes patient may panic and ‘shoot it down’ with extra insulin without considering the consequences on a long-term basis. In my view, such behaviour has a similar function as the distancing effect of some of the emotion-focused coping strategies. At the other hand, as also pointed out by Lazarus & Folkman, some emotion-focused coping strategies can be problem-focused at the same time (cf. the diazepam pill example above). In the case of a hyperglycaemia, the diabetes patient may actively try to avoid panicking (emotion-focused coping) and to have patience with the

blood sugar being out of range temporarily, in order to avoid taking extra insulin, which could contribute to the source of the problem in the long run (i.e., problem-focused coping). In my view, then, the key concepts to distinguish between these two approaches are to be 'confrontive' or to be 'distancive' when facing this kind of problem. Since diabetes is a controllable disease in which patient self-care is of paramount significance, I found this distinction to be most relevant. I therefore decided on this difference to be my primary concern when categorising the coping strategies.

Having introduced this distinction, I went back to start from scratch in categorising the coping strategies while employing this new method. Re-reading all the passages on coping, i.e. the coping strategies, I focused on one particular question in order not to get confused: 'Is this particular coping strategy an example of confrontive or distancive coping?' However, when studying coping it is necessary to be specific in terms of which kind of problem the coping process is about (Lazarus, 1999). And it confused the categorisation process that with relation to diabetes disease management there are many kinds of problems to which a patient can have a confrontive or a distancive approach. To name a few examples found in the interviews, a patient may face problems in obtaining good metabolic control, problems concerning late complications or health problems not being related to diabetes, problems in communicating with health professionals, problems in operating DiasNet, problems being concerned with the DiasNet project, problems in understanding scientific explanations, family and marital problems, problems at work, problems in social life, and problems concerning sports activities. Therefore, it soon became clear that I had to further specify in terms of which problem the primary relational difference should be identified. I decided on metabolic control as the focal concern, as this issue is the *raison d'être* of DiasNet. Having decided on this second conceptual issue, I once again went back to start from scratch in categorising the coping strategies. In this process I was focusing on one single question: 'Is this particular coping strategy an example of a confrontive or distancive approach to problems in obtaining metabolic control, i.e., does it have a primary focus on constantly keeping the blood sugar level within a reasonable range (the confrontive approach), or does it have some other primary goal (the distancive approach)?'

In deciding on these primary conceptual distinctions, I may be criticised for choosing a medico-centric perspective (cf. chapter 1), i.e., deciding on a focus on metabolic control at the expense of alternative perspectives, which may be found in my material. However, my definition of the most relevant relational difference in this study does not reflect a judgment on

my part concerning what is the most important issue that a patient ought to focus on in dealing with diabetes. Instead, my choice of perspective is motivated in two ways, which differs from merely taking a medico-centric approach. Firstly, my primary concern is to study DiasNet as a learning artefact. As a tool DiasNet was primarily built to support doctors in dealing with the problems of metabolic control in their patients. When being presented to the patients as a learning tool, then, DiasNet carries this agenda with it. Hence, as a descriptive method, I find it most relevant to study to what extent the patients' actions are in alignment with this agenda when studying DiasNet as a learning tool. Secondly, the relational difference is not defined as an instrument to distinguish between 'good' and 'bad' coping. As pointed out by Lundman, even 'experts' among diabetes patients sometimes make use of temporal emotional distancing. In terms of my definition above, they temporarily suspend a primary focus on constantly keeping their blood sugar within a reasonable range. This strategy was also found among many of the patients I spoke with. Importantly, even if one accepts the 'doctor's perspective', such 'distancive' coping strategies may then be an example of 'good' coping. On the other hand, some may argue that, in case the explanation of this strategy is that a patient is trying to avoid tedium, this coping strategy in fact is 'confrontive' instead of 'distancive', because tedium is an impediment to good metabolic control. Hence, such a strategy may be motivated by a focus on keeping up metabolic control in the long run. Yet, if a patient is talking about 'taking a day off', I find it a more appropriate description of the function of this coping strategy, and closer to the patient's own words, to describe it as 'distancive' coping with relation to a 'constant' focus on metabolic control. Nevertheless, in line with this discussion, one may ask 'what is a reasonable range of blood glucose measurements?' and 'who is to define this range – the doctor or the patient?' However, 8 out of 9 patients I interviewed reckoned with an ideal of blood glucose measures within a range between 4 – 10 mmol/l (according to their answers to the questionnaire), which is within the recommended range as specified by (Lendal et al., 1995). Furthermore, all of those patients had a personal ambition being very close to this ideal. Therefore, in these cases, since there is a match between what my informants say themselves and what is recommended by health professionals concerning metabolic control, the term 'a reasonable range of blood glucose measurements' is not controversial.

Concerning the choice of a conceptual label for the basic distinction between confrontive and distancive coping, I regard it as two different 'coping functions'. Within the Lazarus-Folkman approach the traditional concept of 'coping function' denotes a difference between two kinds of

changes in the way a person is trying to alter a troubled person-environment relationship, either to change the realities of this relationship (problem-focused coping), or to change the emotional response to it (emotion-focused coping). In other words, various instances of coping are 'functioning' in terms of introducing a relational difference in terms of either altering the reality of the situation or the person's emotional response to it. However, as pointed out above, both problem-focused and emotion-focused coping can be instances of either the confrontive or the distancive approach. In my view, then, within diabetes care the latter distinction is more fundamental than the two traditional coping functions (emotion-focused and problem-focused coping), because it denotes two different approach alternatives to dealing with a disease management problem. Therefore, in this study I will alter the traditional use of the concept of 'coping functions' to denote a fundamental relational difference in terms of two approaches being either 'distancive' or 'confrontive'. To be more precise, the term 'coping function' denotes how any given coping strategy relates to a primary choice of approach to disease management problems in diabetes being an instance of either a 'confrontive' or a 'distancive' approach. Similarly to the traditional concept of coping functions these concepts are employed as two basic coping categories. Unlike the Lazarus-Folkman approach, however, I will use this distinction as a dichotomy to distinguish between different coping strategies as analytical concepts. But, since many coping strategies can be employed in a single process of coping, it is possible that it represents both confrontive and distancive coping functions.

4.3.3 Coping forms and coping types

Above I described the primary concern of a coping analysis in terms of the 'function' of a given coping strategy, i.e., determining whether a given coping strategy is an instance of a confrontive or a distancive approach to dealing with a certain disease management problem. A secondary concern is to further describe a given coping strategy in terms of its 'coping form', i.e., the way in which a certain coping function shows. Since, for example, problem-focused coping can both be an instance of confrontive and distancive coping, it is necessary to distinguish between the function of a coping strategy and how it shows (i.e., as problem-focused coping in this case). Hence, following the completion of dividing the coping strategies into the two groups, 'distancive' and 'confrontive' coping, I therefore decided to reintroduce a number of concepts in order to further describe the coping strategies in terms of their behavioural characteristics.

As I have chosen an alternative set of basic coping functions, I suggest that the traditional pair of concepts concerning coping functions (emo-

tion-focused and problem-focused coping) can be regarded as different 'forms' of coping. In addition to these coping forms I will employ a number of other concepts found in the literature, which I found particularly relevant in my analysis. As stated above, these concepts included meaning-focused and routine-focused coping.

To help employing these four concepts as consistently as possible, I organised them in a matrix structure being defined by two axes (see Figure 4.1 below). One axis distinguishes acute coping from long-term coping, and the other axis distinguishes internal from external coping. This way, the four quadrants in the matrix are: Acute internal coping, acute external coping, long-term internal coping, and long-term external coping. As indicated above, it follows the original definition of 'emotion-focused' and 'problem-focused' coping to distinguish between internal and external coping this way. When employed in this study, however, it is necessary to consider how this internal-external distinction applies to coping with diabetes. In this study, then, the term 'internal' refers to the psyche, not the body (as in biofeedback), whereas 'external' both refers to actions outside

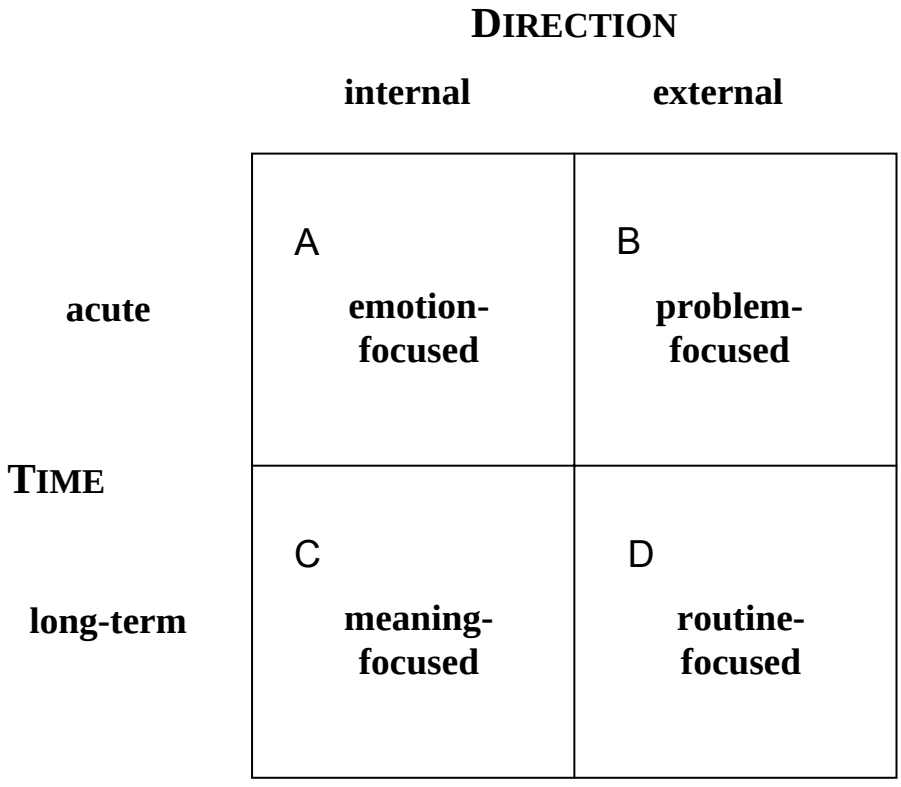

Figure 4.1: Four coping forms, inspired by (Lazarus & Folkman, 1984), (Folkman, 2001), and (Lundman, 1990), organised in terms of two scope dimensions, time, and direction (the latter dimension, the scope in terms of an internal or external direction, does not apply to the body, but to the psyche).

of the patient's body (which – of course – may mediate changes inside of the body), as well as a sharpened awareness of bodily reactions (e.g., subjective blood glucose estimations). Furthermore, concerning the issue of coping in chronic diseases discussed above, I understand the concepts of emotion-focused and problem-focused coping as denoting 'acute' coping in order to be as close to the original definition within the Lazarus-Folkman approach as possible. Emotion-focused coping is thus regarded as 'acute internal coping', and problem-focused coping as 'acute external coping'.

In chain with this reasoning, internal coping on a long-term basis will be categorised as 'meaning-focused' (inspired by Folkman 2001), whereas external coping on a long-term basis will be categorised as 'routine-focused' (inspired by Lundman 1990). Meaning-focused coping refers to one's deeper values and view of life, i.e. having to do with putting an actual problem in a larger (long-term) perspective, which changes the relational meaning of the actual problem. Routine-focused coping is identified as extravert behaviour and, thus, is distinguishable from both emotion-focused coping and meaning-focused coping. Furthermore, it is distinguishable from problem-focused coping in the sense that it does not serve to handle an acute problem. Instead, it is focused on avoiding certain types of problems by exercising a certain pattern of behaviour. In following the coping definition employed in this study as stated above, neither meaning-focused coping, nor routine-focused coping are necessarily associated with an experience of the actual situation as being 'unpleasant' or 'dangerous' – however, as a routine, it was originally initiated by the appraisal of a stressful situation.

When employing these concepts to categorise the coping strategies in the two groups, it showed that all of the four coping forms can represent both a distancive and a confrontive approach, resulting in eight different types of coping strategies, as illustrated by the cube structure below (see Figure 4.2, next page).

In addition to these coping forms, there still were a number of coping strategies, which were difficult to fit into this clear-cut picture. All of these had to do with 'seeking social support' in some way or another. When reading these passages, I felt that these coping strategies were not merely focused on finding a solution to a problem, or to get emotional support, or the like. Instead, I got the impression that the patients merely wanted to be in contact with another human being. As already discussed above concerning NTS conversations, Howells observed that 'Contact, independent of content, appears to be a key element.' (Howells et al., 2002; see also Falk, 1996, p.35). In further support of this thought, I

speculated that a person might feel 'lost' and 'alone' when encountering a stressful situation. As such, coping with feelings of being alone may be categorised as an emotion-focused coping form. However, seeking social support is not only an internal way of coping, as it implies extravert behaviour. Furthermore, it was my impression that this form of coping often is a vehicle of the other forms of coping, for instance, to seek comfort in talking to friends or relatives (emotion-focused coping), to take a doctor's advice on some problem (problem-focused coping), to feel committed to health professionals in following a treatment plan (routine-focused coping), or through conversations with fellow patients to find new meaning in a frustrating situation by putting the challenges of diabetes disease

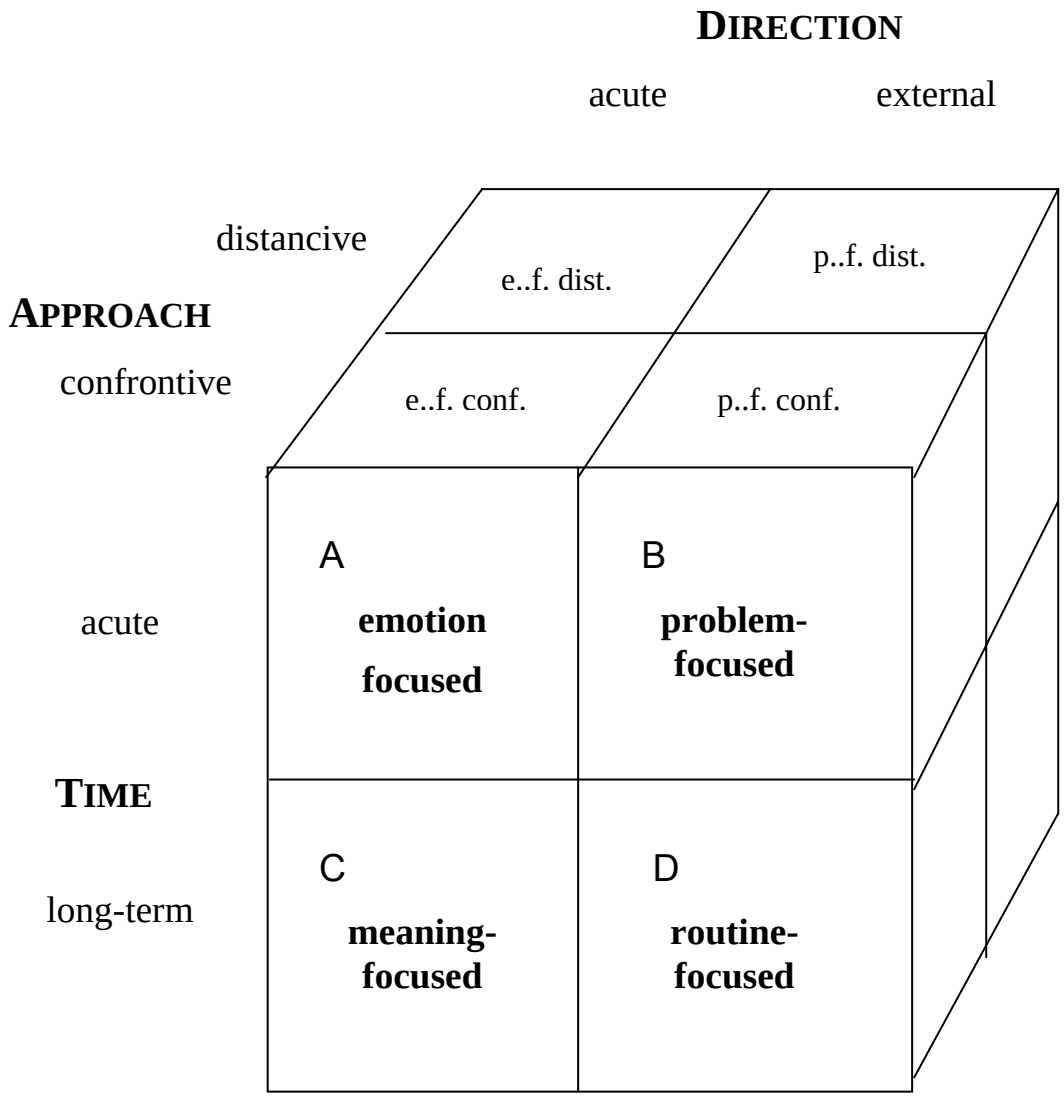

Figure 4.2: Eight types of coping strategies, illustrated by a cube structure consisting of a matrix of four types of coping forms (organised in terms of two scope dimensions, time and direction) found in both types of coping functions (organised in terms of two alternative approaches, confrontive or distancive).

management into a new perspective (meaning-focused coping). Hence, following the logic of the matrix structure above (cf. Figure 4.1), I therefore added a fifth coping form being 'contact-focused coping' to be regarded as a coping form in itself. In my material, contact-focused coping was found in both groups of coping strategies, thus serving both a confrontive and a distancive coping function.

To sum up, in addition to the concepts of the two coping functions the coping strategies were categorised in terms of five coping forms, which I will describe as follows:

- emotion-focused coping: acute, internally directed coping focused on regulating the emotional response to a stressful situation.
- problem-focused coping: acute, externally directed coping focusing on changing the realities of a stressful situation.
- meaning-focused coping: long-term, internally directed coping focused on enduring a stressful situation by changing the relational meaning of it.
- routine-focused coping: long-term coping focused on exercising habits of externally directed behaviour.
- contact-focused coping: actions motivated by a basic need of being in contact with another human being when encountering a stressful situation; often found as a vehicle of other coping form.

Each of the five coping forms were found in the two groups of confronting and distancing coping strategies, resulting in ten different 'types' of coping strategies (see appendix F, illustrating all 10 types). In what follows, I will present these types by listing all the sub-groups of coping strategies, which were categorised under each coping type. Some of the categories are in the form of an expression (in italics) being inspired by an utterance from one of the patients, which characterises a certain approach. In the parentheses the list also carries information on quantitative aspects in terms of, first, the number of patient interviews, and, second, the total number of passages, which were coded by each category.

Emotion-focused confrontive coping (9/83): Confirmation (9/44), knowledge/ *a good explanation helps* (6/18), accepting the hassle of disease management (5/6), avoid unrealistic expectations (4/6), optimism, hope (3/7), to express feelings of dissatisfaction (2/2).

Emotion-focused distancive coping (9/138): Resignation (8/35), neglectance (8/24), denial (7/11), blaming others (6/20), avoidance (5/22), withdrawal, concealing (5/9), self-pity/ day-dreaming (4/4), non-responsible ways of expressing frustrations (6/25).

Problem-focused confrontive coping (9/146): Focusing on developing means to handle an actual stabilisation problem (9/63), own problem-solving in cases of imminent hypo- or hyperglycaemia (8/42), gathering data to solve a problem (8/27), ask the clinicians for advice (6/12), testing the counter-regulation hypothesis (4/6), using SMBG to combat acute fear of late complications (3/14), keeping physiological data in check (3/3).

Problem-focused distancive coping (6/18): Shortsighted focus on removing trouble (2/4), counting on the clinicians to take away problems (6/13), eating like a bird to diminish the intake of insulin (1/1).

Meaning-focused confrontive coping (9/118): Making diabetes and disease management a part of one's identity (9/25), motivating thoughts (8/56), *it could be much worse* (8/14), positive reappraisal (6/6), *eat what you like and take more insulin* (4/6), *diabetes is a pall you need to care about* (4/6), reflecting on questions like '*what should I learn from getting diabetes*?' (3/11), *other patients can learn from my story* (1/1).

Meaning-focused distancive coping (6/25): *Life quality is more important than physical health* (5/10), *once in a while it is good to lower one's disease management ambitions temporarily* (5/16).

Routine-focused confrontive coping (9/140)**:** Trying to learn something new everyday (9/34), daily preventive routines (8/22), staying focused with DiasNet (6/30), *it is an ideal to lead a stable life* (6/24), minor adjustments of blood sugar level (5/16), taking account of carbohydrates (5/13), taking extra SMBG in risky situations (5/12), doing regular exercise (2/4).

Routine-focused distancive coping (9/59): *Habits make you free to be more unaware of diabetes* (7/40), making ill-informed disease management decisions (7/14), being a passive recipient of health care (6/10), running an elevated blood sugar level to be on the safe side (2/3).

Contact-focused confrontive coping (9/67): *It is essential to receive feedback from the clinicians* (9/57), *project meetings with the other patients were very inspirational* (6/9), appreciating support from family and spouse (2/2).

Contact-focused distancive coping (5/10): Family surveillance (2/5), *nice to feel that we are 'in the same boat' as patients* (1/2), tips from a diabetic friend on how to break the rules (1/1), *getting a job helped me in combating my fear of late complications* (1/1).

After having presented these categories being identified through a cyclical process of coding, categorisation, clarifying concepts, recoding, and so forth, I will describe how they may help in analysing the integration of DiasNet into the health behaviour of the patients.

4.4 Coping and CDDM

The following analysis of the way in which DiasNet is integrated into and influences the disease management behaviour of the patients is founded on the concept of coping as a way to identify and analyse health behaviour. Hence, the analysis was based on a series of coding phases. As described above, in a first coding phase the nine patient interviews were thoroughly analysed to code every instance of coping as specific coping strategies and to categorise these as one of the ten coping types. As a final part of this phase, a group interview, which that was made with some of the patients a year before, was also coded according to these coping types in order to look at changes in the statistical representation of each coping type. Next, taking the identified coping strategies in the nine patient interviews as the foundation for the study of DiasNet's integration, a second coding phase was looking into these text passages in order to identify and categorise artefact use according to the artefact concepts described in chapter 3. Some of these instances of artefact use were directly or indirectly related to the use of DiasNet, while some were not. In what follows, the first group will be labelled instances of computerized diabetes disease management (CDDM). Following these two phases of coding it was then possible to study the relationship between the categories.

In what follows, I will present an analysis being based on the statistical facilities of NVIVO 2.0, as I have based my discussion on extracting data by way of queries. These queries consist of combinations of codes pointing to strings of text, which sometimes overlap each other. Working with more than fifteen hundred passages coded in various ways it was not feasible to read through and control the relevance of all such coincidences of coding for the current analysis in this chapter. Therefore, in this chapter, the assumption is made that most of the time the overlapping codes are pointing to text strings in which patients are discussing how DiasNet related artefacts come into play in a certain coping process. Thus, by referring to this assumption I will interpret such overlaps as instances of coping being related to CDDM, while not necessarily being mediated by DiasNet in any direct sense.

4.4.1 Coping forms and functions in Spring 2003 and 2004

A first look into the material is focusing on the character of the health behaviour found in the nine patient interviews. Figure 4.3 (next page) illus-

trates the percentage of each coping type in the nine patient interviews, which were carried out in Spring 2004. Practically, all ten coping types were found in every patient interview, except meaning-focused distancive coping, which were only found in six interveiws (i.e., six patients), and contact-focused distancive coping, which were found in four patients.

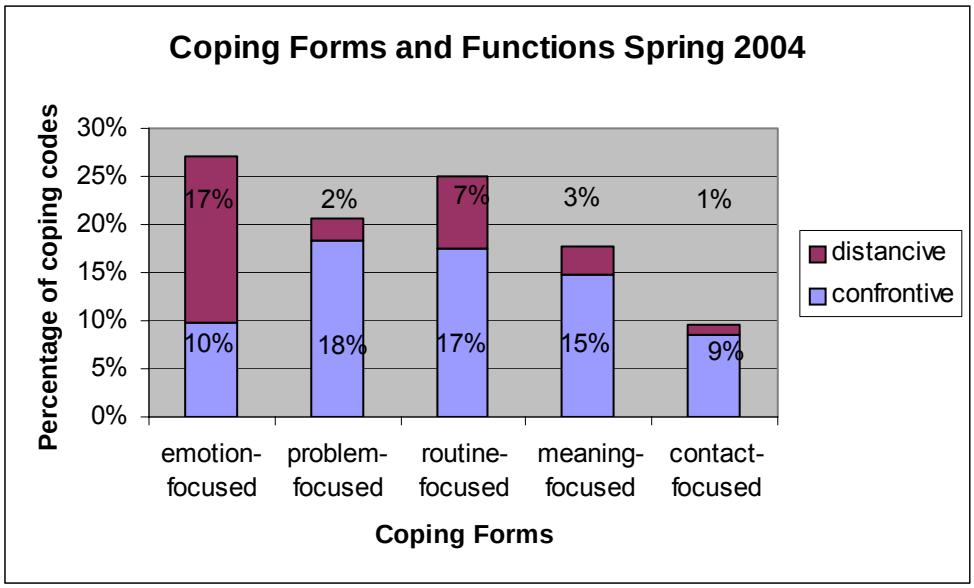

Fig. 4.3: Coping forms and coping functions Spring 2004.

When comparing the five coping forms, emotion-focused coping appears to be the most common (27,1%), followed by routine-focused (24,6%), and problem-focused (20,6%) coping. Meaning-focused coping is also fairly common (18%), while only 9,7% of all coping strategies are contact-focused coping.

Looking into coping types, it appears that problem-focused confrontive coping is the most common coping type (18%). This may not be surprising, since prototypical examples of confrontive coping is problem-focused coping. In a similar manner, it may be as expected that emotion-focused distancive coping also plays a major role (17%). More surprisingly, routine-focused confrontive coping appears to be as common as these coping types (17%).

If we compare coping functions and coping forms, it appears that confrontive coping is most common in all coping forms, except emotion-focused coping in which the distancive approach is the most common (64%). This may not be surprising, since prototypical examples of emotion-focused coping is to distance one-self from un-solvable problems. However, a distancive approach to problem-focused coping was also found, but only in 10% of passages of this coping form, which may not be

surprising. More interestingly, only 17% of meaning-focused coping is distancive. This may indicate that this coping form primarily is used in finding a meaning in the laborious task of obtaining metabolic control. What is also interesting is that 10% of contact-focused coping is distancive, which may indicate that patients are primarily seeking social support to obtain metabolic control, and not to be distracted from this task. At the other hand, it appears that a fair amount of routine-focused coping is distancive (29%). When keeping in mind that this coping form is wide spread in the material, this may indicate that routine-focused coping not only characterises a fair amount of the patients health behaviour, but also that far from all of their disease management routines are 'good habits', in terms of a focus on metabolic control.

One may speculate that if the goal is to promote confrontive coping, there is a large potential in finding ways to reduce emotion-focused distancive coping and distancive routines. In relation to this question, one could ask if the DiasNet project entails such methods. Interestingly, when comparing the above findings with the distribution of coping in the group interview one year earlier it appears that the most legible change is within emotion-focused coping (see Fig. 4.4 below).

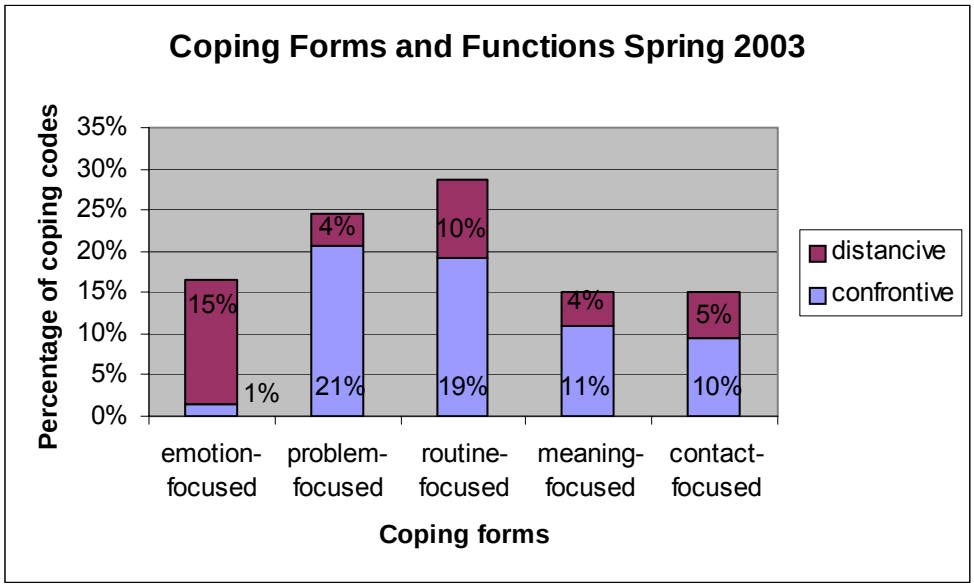

Fig. 4.4: Coping forms and coping functions Spring 2003.

In the group interview from Spring 2003 only 1% of the coping codes are emotion-focused confrontive coping, while this coping type has risen to 10% after the DiasNet project, and while the share of emotion-focused distancive coping has decreased from 94% to 64%. It should be pointed out, however, that it is not easy to make a direct comparison of these distributions. Firstly, the group interview represents a much smaller amount

of material than the nine patient interviews, and secondly, the situation from which it was taken may have influenced the group discussion to increase the share of emotion-focused confrontive coping strategies.

Nevertheless, due to this clear change in the distribution, the relationship between emotion-focused confrontive coping and the introduction of DiasNet will be studied more closely in what follows. Later, I will also take up the question concerning distancive routines.

4.4.2 Confrontive coping and CDDM

Focusing on the relationship between CDDM and the two approaches to health behaviour, the pie chart below (see Fig. 4.5) illustrates the amount of passages in the nine patient interviews (Spring 2004) being coded as confrontive or distancive coping in combination with codes concerning CDDM. All four possible combinations are found in all nine patient interviews, and they are mutually exclusive, since no passages were found in their joint set.

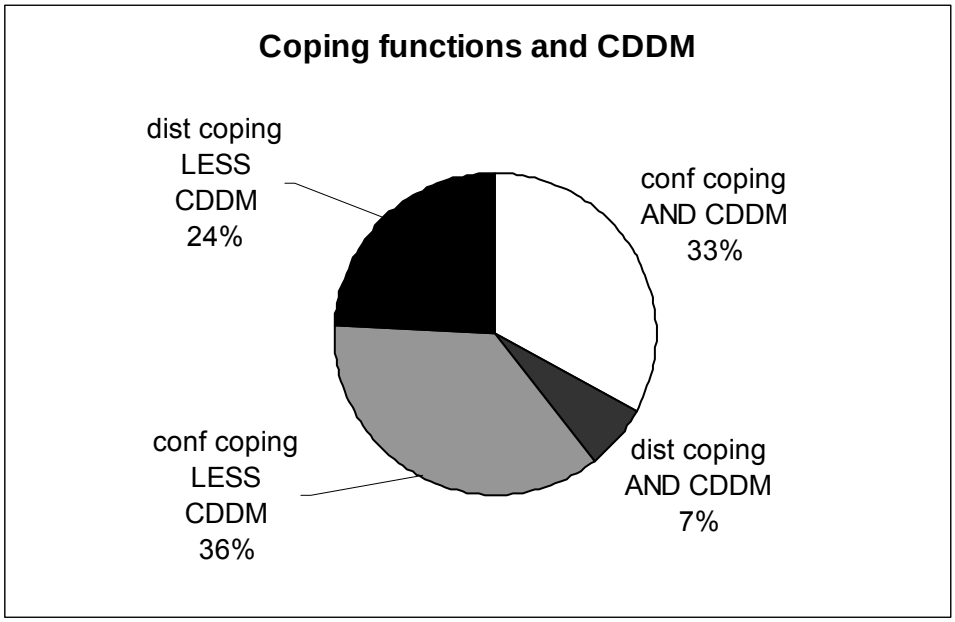

Fig. 4.5: Coping functions and CDDM.

First and foremost, the pie chart shows that CDDM is talked about in relation to 40% of all coping coded in the nine interviews. Hence, a considerable amount of the patients' coping, i.e., health behaviour, discussed in these interveiws is related to CDDM.

Next, it shows that confrontive coping amounts to two thirds of all coping, which is seen as a fortunate indication. However, while confrontive

coping amounts to 80% of CDDM, it only amounts to 60% of non-CDDM. At the same time, 48% of all confrontive coping is related to CDDM, while only 23% of all distancive coping is related to CDDM. This may indicate that confrontive coping is closer related to CDDM than non-CDDM.

As a further step, this analysis is looking into the relation between CDDM and coping types. The bar chart below (see Fig. 4.6) illustrates in how many patient interviews the various coping types are found combined with codes concerning CDDM (and non-CDDM).

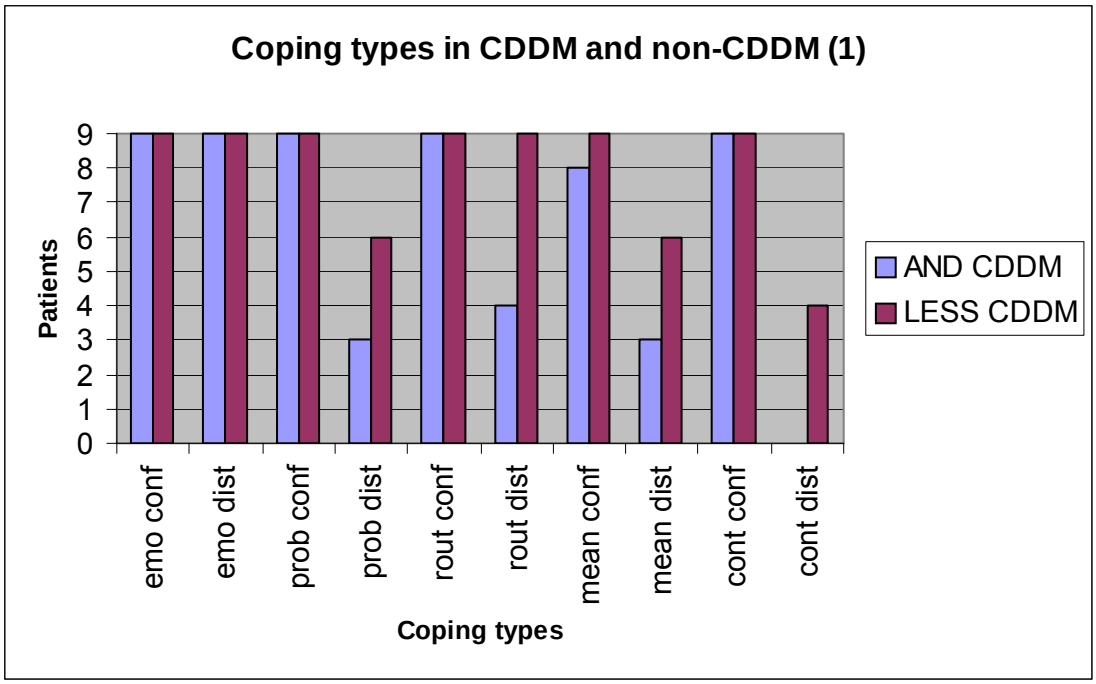

Fig. 4.6: Coping types in CDDM and non-CDDM (patients).

The general picture shows that CDDM is related to all coping types, except contact-focused distancive coping. Furthermore, most coping forms of the confrontive type dominates the distancive type (when related to CDDM). And if we look at the confrontive coping types being related to CDDM it shows that most of them are found in all nine patient interviews, except meaning-focused confrontive coping, which is found in eight patients. The diagram thus makes it clear that CDDM is in closer relation to confrontive coping than to distancive coping.

To get a clearer view of the relative extension of the coping types in the material, I have extracted the number of coded passages, instead of only counting the number of patient interviews in which a certain coping type is found. Figure 4.7 below (next page) shows the amount of passages coded with each coping type in all nine patient interviews (Spring 2004).

(The percentages of these amounts are illustrated by Fig. 4.3 above). Furthermore, each bar representing a certain coping type is divided into the amounts related to CDDM and non-CDDM. This way, it is possible to see how much of each coping type is related to CDDM, as well as the share of these combinations compared to the overall picture (all coping).

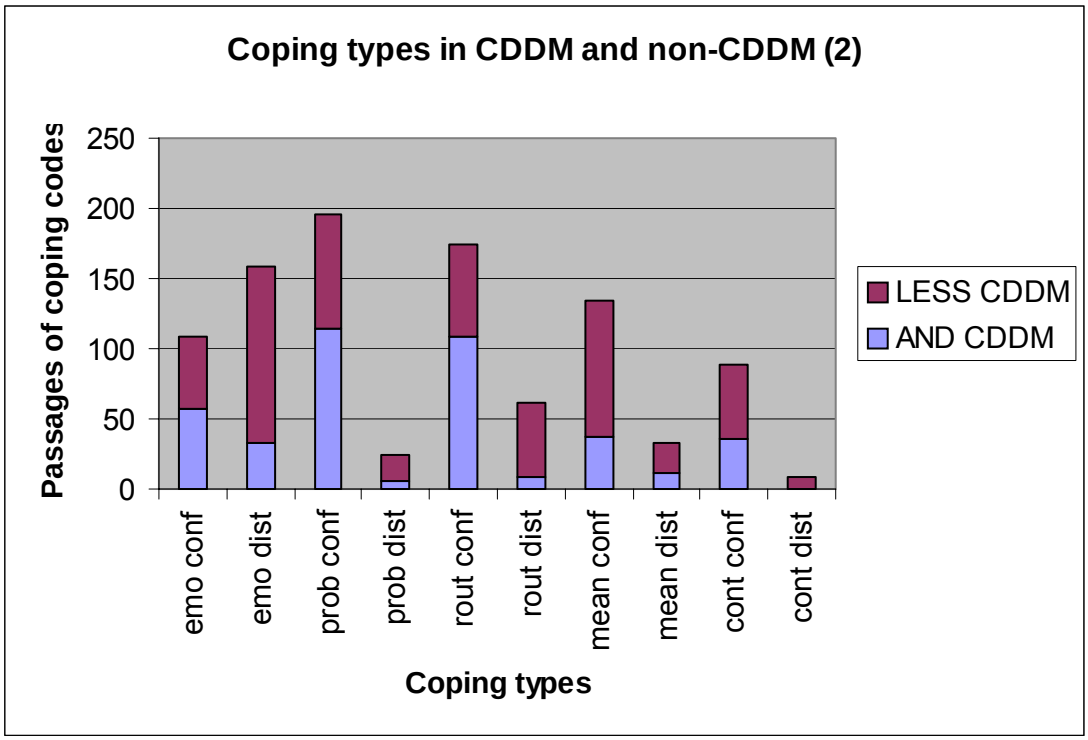

Fig. 4.7: Coping types in CDDM and non-CDDM (passages).

Focusing on confrontive coping being related to CDDM it appears that two types stand out with more than 100 passages each, namely problem-focused and routine-focused coping. At the same time it appears those two coping types in particular are in relation to DiasNet, since more than half of their total passages are related to CDDM. Hence, not only do these two coping types play a major role in the overall coping, it is also the case that these coping types to a large extent are related to CDDM. In fact, these coping types amount to 54% of the coping related to CDDM. Furthermore, it appears that in three coping types half of the passages are related to CDDM, being emotion-focused, problem-focused, and routine-focused confrontive coping. Topping this list is routine-focused confrontive coping (62%), and this may indicate that the DiasNet related artefacts are well suited to be integrated into 'good habits'. Also problem-focused coping has a fair share of passages related to CDDM (58%), and this may not come as a surprise. But what may be surprising is that CDDM is also heavily related to emotion-focused confrontive coping (52%). (Later, I will return to the question whether this finding may cast some light on the

issue stated above, namely whether the DiasNet project included elements to promote emotion-focused confrontive coping). Furthermore, it appears that contact-focused coping being represented in all nine patient interviews is only found in a minor part of the coded passages. And finally, it is observed that even though meaning-focused coping being related to CDDM is found in almost as many patients as emotion-focused coping, it is not as closely related to CDDM when considering the ratio of passages being related to CDDM.

4.4.3 Distancive coping and CDDM

Concerning distancive coping being related to CDDM it only amounts to 7% of all coping, as illustrated by the pie chart above (Fig. 4.5). When looking at the two bar charts to further identify which types of distancive coping, it appears that practically all of it is emotion-focused distancive coping, which is found in all nine patients. The other distancive coping types being related to CDDM are only found in less than half of the patients, and in much fewer patient interviews and passages than the same coping type not being related to CDDM. The largest difference is found in routine-focused distancive coping, which is found related to non-CDDM in 54 passages in all nine patient interviews, whereas the same coping type being related to CDDM is only found in eight passages (13%) in four patient interviews. Also, contact-focused distancive coping being related to non-CDDM is observed in half of the patient interviews, while this coping type is not registered as related to CDDM at all.

Hence, this indicates that most of the distancive coping types are found in relation to CDDM, but that for the most part it has to do with emotion-focused distancive coping. Furthermore, the above analysis may provide a part of an answer to one of the questions raised above. While it was observed that far from all disease management routines are ‘good habits’, and while the question was raised whether some of the ‘bad habits’ could be related to CDDM, it now appears that only a minor part of the routine-focused distancive coping has been related to CDDM.

4.5 Coping, adoption and empowerment

The above analysis has been looking into coping in the nine patients in relation to the introduction of DiasNet. It appears that a large portion (40%) of the coping strategies discussed by the patients a year after the onset of the Diabetes project is related to DiasNet. Bearing in mind that the interview was partly focusing on DiasNet, while also addressing many other aspects of the patients’ experiences, this can hardly be taken as a measure of the degree to which DiasNet is integrated into the coping of the patients. It may, however, be taken as an indication that DiasNet is

related to a substantial amount of their coping. Hence, concerning the adoption theme, this indicates that the group of patients have adopted DiasNet as an integrated part of their health behaviour to a fairly large extent.

Furthermore, the analysis provided some indications of how DiasNet has been adopted in terms of the character of the coping being related to it. Firstly, concerning the basic distinctions between confrontive and distancive coping the analysis indicates that there is a closer connection between CDDM and confrontive coping than distancive coping, as almost half of the confrontive coping is related to DiasNet, while only a quarter of the distancive coping is related to CDDM. This raises the question whether these findings indicate that DiasNet promote confrontive coping instead of distancive coping, or that confrontive coping is more open to the adoption of new artefacts like DiasNet. Since this study only to a slight degree is open for a comparison of the patient's coping at the beginning of the Diabetes project and a year after, it does not provide an answer this question.

Next, concerning which coping types were most commonly being related to DiasNet it was found that in three confrontive coping types more than half of the passages are related to CDDM, namely routine-focused, problem-focused, and emotion-focused confrontive coping. Concerning the distribution of the latter coping type, emotion-focused confrontive coping, this has increased remarkably from the first interview to the next. Hence, it seems that the way DiasNet primarily has been adopted into the patients' health behaviour is to support long-term preventive behaviour, acute problem solving, as well as in keeping up a good spirit. In addition, contact-focused and meaning-focused coping were found in almost all patients, however, these codes were not used as often as the above mentioned. Concerning distancive coping types, two observations were made. Firstly, that emotion-focused coping was most commonly related to CDDM, while at the other hand, routine-focused distancive had the weakest relation to CDDM (apart from contact-focused distancive coping, which were not at all related to CDDM). Hence, it seems that DiasNet to some degree is related to behaviour like avoidance, while at the other hand it is only slightly related to 'bad habits'.

Now, turning to the second theme of this study, it may be possible to interpret findings on coping in terms of patient empowerment. From a patient-centred perspective, coping analysis could assist in clarifying patient specific health behaviour, without making any judgements about 'good' and 'bad' coping, in order to facilitate a patient's own process in defining his or her disease management goals. At the other hand, from a more medico-centric perspective it may also be possible to point out to which

degree DiasNet has contributed to patient empowerment within the Diabetes project. I will therefore present a way to rank the various coping types in terms of their contribution to empowerment. The ranking system is based on a certain choice of perspective on a diabetes patient's disease management activity, namely that its primary object is to obtain metabolic control.

Firstly, concerning coping functions, confrontive coping relating to obtaining better metabolic stabilisation will be conceived of as contributing to empowerment, while distancive coping does not. Here, one should keep in mind that coping often is a multi-faceted process consisting of a variety of coping types, which may all contribute to this process, e.g., that distancive coping may save the patient from developing tedium. However, distancive coping would still be indicating that a patient is facing difficulties in constantly doing what is necessary to obtain metabolic control.

Secondly, concerning confrontive coping forms, there is a distinction between external and internal coping. External coping is more directly relating to the physiological facts of the fundamental breakdown situation, i.e., the lack of endogenous insulin production, and the resulting task of obtaining metabolic stabilisation, than internal (non-somatic) coping. Hence, problem-focused and routine-focused coping is closer to the primary object of diabetes disease management than emotion-focused and meaning-focused coping. Furthermore, even though it is good to be able to solve problems having to do with an unstable metabolic control, it is closer to the primary object (of obtaining a constant metabolic control) to avoid such problems in arising. Hence, long-term preventive coping has a higher rank than acute problem-focused coping. Likewise, meaning-focused confrontive coping can be considered more directly related to the object of metabolic control than acute emotion-focused coping, since meaning-focused coping has to do with integrating an orientation toward this object into one's identity more deeply.

Hence, concerning empowerment confrontive coping has a higher rank than distancive coping, and among confrontive coping routine-focused coping is topping the list, followed by problem-focused, meaning-focused, and emotion-focused coping. Contact-focused confrontive coping is not a part of this list, but may function as a vehicle for all of them.

Consequently, building on the results above concerning adoption it seems that DiasNet has contributed to patient empowerment. Firstly, CDDM seems to have a closer relation to confrontive coping than to distancive coping. Secondly, the two coping types which seem to have the closest relation to CDDM, routine-focused and problem-focused confrontive

coping, are topping the ranking system of coping types contributing to empowerment. In addition, emotion-focused confrontive coping, which is also contributing to patient empowerment, also to a considerable degree seems to be related to CDDM. At the other hand, there also seems to be some relation between CDDM and emotion-focused distancive coping, which is not contributing to patient empowerment from a medico-centric point of view.

As a closing remark, the above analysis of the integration of DiasNet has only been focusing on the character of health behaviour, which is found in relation to DiasNet. Hence, this analysis does not provide much insight into how DiasNet is integrated, i.e., which aspects of DiasNet and how it is used as a tool. These are the questions I turn to next.

5 Interface and copability: Analysis of artefacts and the mediation of health activity in IDDM

How does DiasNet present itself as a tool for the participants? This interface analysis of DiasNet seeks to clarify how DiasNet mediates the health behaviour of the patients. The concept of interface is understood in terms of mediation, i.e., something between subject and object, and not something between a subject and the computer technology on which DiasNet is based. DiasNet is a complex tool compared to, e.g., SMBG meters or insulin pens. Hence, the various purposes of using DiasNet are pointed out in terms of use forms. Also, the analysis points out artefacts at all artefact levels being employed in the mediation of health behaviour. Both aspects are discussed in relation to the issues of adoption and empowerment.

5.1 DiasNet use forms

Four different use forms were identified in the 9 patient interviews:

- **Registration**: When being introduced to DiasNet the patients were instructed to enter their home monitoring data from three consecutive days on a weekly basis. A year later, after the Diabetes project had been closed down, many patients kept on using DiasNet this way, however, most often in a less rigorous manner and for a variety of reasons (to be described later), including as a necessary step to use DiasNet in other ways (i.e., the following use forms).
- **Reflection**: This use form characterizes the patient's own effort in studying his or her own situation as represented by the visualisation of the home monitoring data, as if DiasNet were a kind of mirror – or various kinds of mirrors – reflecting the patient's current situation, and initiating reflections within the patient in terms of considerations on his or her disease management.
- **Exploration**: Using DiasNet this way is different from the use form above, as the patient is employing some of the facilities within DiasNet to make virtual experiments with changes of insulin regimen or diet, either to find new solutions, or merely to play and learn about the metabolic dynamics.
- **Intervention**: Finally, using DiasNet this way the patient is oriented toward making actual interventions in 'real life' concerning disease management changes. Mostly, the health professionals guided these interventions, however, in some cases the patients also made their own interventions inspired by DiasNet.

These concepts are understood as a variety of approaches to using DiasNet, i.e., as ways in which the toolness of DiasNet appears. The concept of use forms carries an ambiguity to it, much like the word 'screwdriver'. At the same time, it denotes a certain kind of toolness and a certain kind of action being mediated by the tool. Within the school of CHAT, an action is described in terms of which goal it is relating to. My method in identifying the use forms has thus been to identify a variety of sub-goals, which are sub-ordinated to the primary goal in using DiasNet (which was described above in the coping analysis as the object of finding out how to handle the primary breakdown situation of the mal-functioning pancreas). Hence, concerning the ambiguity of the concept of use forms, both denoting actions and tools, my method of identifying use forms accentuates the concept of actions. In the second part of this chapter, I will accentuate the other half of the toolness and turn to concepts on artefacts in accordance with the concept of artefact types described in chapter 3.

The identification of the four categories was not guided by any theoretical concepts in a top-down manner. Instead, they are the result of a bottom-up coding and categorisation process inspired by grounded theory (cf. chapter 2). When interviewing the patients I was working with three preliminary concepts, being to use DiasNet as a tool for reporting SMBG, for learning, and for decision support. These categories were inspired by DiasNet's development and use history. However, during the coding process it appeared to me that the learning tool category was ill suited for describing a lot of use situations in which the patients seemed to use DiasNet as some sort of mirror – that they were merely taking a good look at their own data upon entering them. At some point during the coding process I was inspired by a phase model of little children's development, found on a box of toys for babies, being to watch, to explore, and to act. To these phases, I added an even earlier phase having to do with actively connecting to the parents by way of giving information about current conditions. By analogy, the resulting four phases seemed to have much in common with the identified uses of DiasNet as a stepwise development of use forms. For some time, the second concept was defined as 'control', since it was denoting a patient's effort to control whether his or her current condition was 'against the rolls' (from Latin, '*contra rotulare*', cf. Beniger, 1986). However, I was advised to change this label, since all of the use forms are contributing to the effort of obtaining metabolic control. Fortunately, I later became aware of an obvious match between some of the use forms and a set of categories concerning empowerment already discussed above: Roter's diabetes-related operationalisation of Freire's concepts on the three key consciousness raising experiences (relating and reflecting on experience, exploration and problem solving, and taking

thoughtful action; Roter, 2001; cf. Ch.1). Inspired by this parallel, I renamed the second phase 'reflection', which at the same time is a better term for using DiasNet as a mirror. Hence, the concept of this second use form has an import from the concept of 'control' into the concept of 'relating and reflecting on experience', i.e., being aware of, and learning from, what is happening. Even though the two concepts of control and reflection are not the same, I will argue that this is not a problem. By referring to the discussion above concerning Bateson's learning theory, I will argue that control is a precondition of reflecting and learning, in the sense that, at any learning level, testing information against a structure of expectations may initiate learning.

In what follows in this part of the chapter, I will describe how the use form concepts may help in analysing the adoption of DiasNet and its contribution to empowerment, while also integrating this analysis with the coping analysis.

5.1.1 DiasNet use forms and coping

The analysis of DiasNet's use forms is founded on the passages of the 9 patient interviews already coded as coping, i.e., instances of CDDM. Like in the coping analysis in chapter 4, the following diagrams are the result of an analysis based on the statistical facilities of NVIVO 2.0. The pie chart below (Fig. 5.1) thus illustrates the distribution of DiasNet use forms in CDDM.

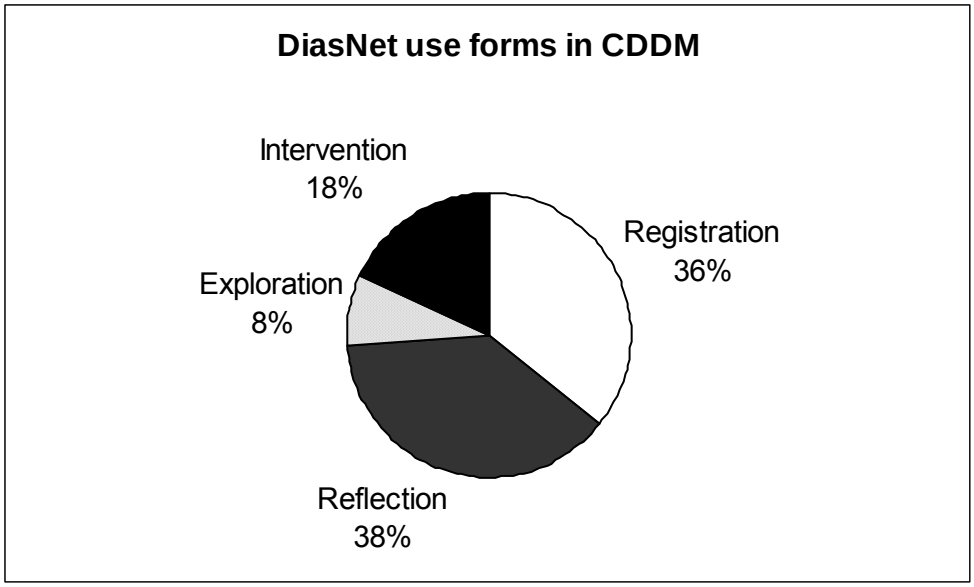

Fig. 5.1: The distribution of DiasNet use forms in coping/ CDDM.

It appears that two use forms are dominating the use of DiasNet, being registration and reflection. The latter is even more common than registra-

tion. This is surprising for two reasons. Firstly, because registration is a necessary step before undertaking the use form of reflection, and secondly, because registration was obligatory for the patients taking part in the Diabetes project in order to establish a collaboration between patient and clinicians mediated between DiasNet. Thus, it seems that the patients in general to a large extent have made use of DiasNet in ways, which were not obligatory for them, especially for reflection. Furthermore, it seems that the exploration facilities of DiasNet have been used only little compared to the other use forms, whereas DiasNet has been used in interventions to a considerable degree.

To further characterise the health behaviour being related to these use forms, the following two diagrams (Fig. 5.2 below, and 5.3, next page) illustrate the distribution of coping strategies also being coded as use forms. Concerning the various combinations of codes concerning coping types and use forms, the first diagram illustrates the relative amount of passages, whereas the second diagram shows the number of patient interviews in which the combinations were found. By comparing the ratio of these coping types within each use form, I will make some observations concerning which coping types characterise each use form, by also referring to how many patients display a certain combination. In further describing these findings, I will not only draw on how the coping types are defined, but also provide some examples from the material.

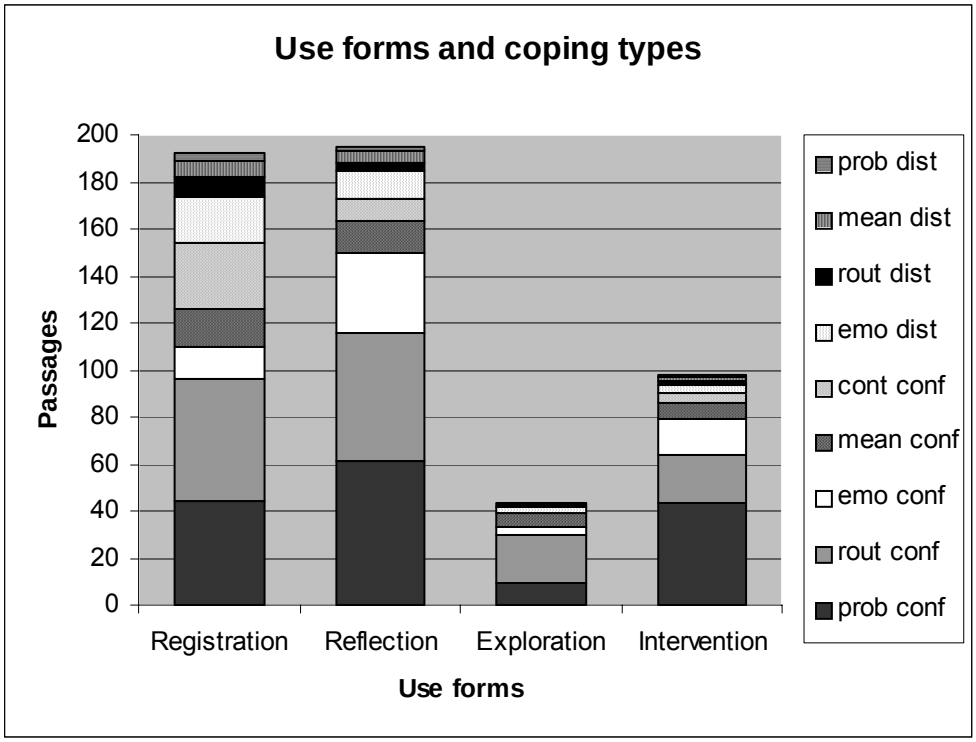

Fig. 5.2: The amount of passages of coded by coping types and DiasNet use forms.

One of the immediate observations is that all use forms are related to several coping types. However, not surprisingly, either routine-focused confrontive coping or problem-focused confrontive coping dominate all use forms. As for routine-focused confrontive coping, all use forms are found in relation to this coping type in all 9 patients, except intervention (8 patients). Concerning the registration and reflection use forms, a match with problem-focused confrontive coping is found in all 9 patients, whereas the combinations with the intervention and exploration use forms are found in 8 and 5 patients, respectively. Hence, these findings indicate that the overall use of DiasNet is mainly characterised by these coping types. Since registration and reflection are the dominating use forms, which are dominated by routine-focused and problem-focused confrontive coping, I will focus on these combinations one after another. Later, I will take a look at which other coping types are characterising each of the use forms.

Concerning the match between **registration** and **routine-focused confrontive coping**, most patients (8) say that the Diabetes project made them take more SMBG, in fact, four patients say that they were used not to take any SMBG before the project began. At the time of the interview a year later, some had built up an SMBG routine being close to the obligatory amount of registration within the project (four measurements each day for three consecutive days on a weekly basis), while other patients had cut this down to only having one or two periods of measurements a month. One patient, Connie, said that this way the project had been a good 'kick start' for her to come out of a bad period, in which she had

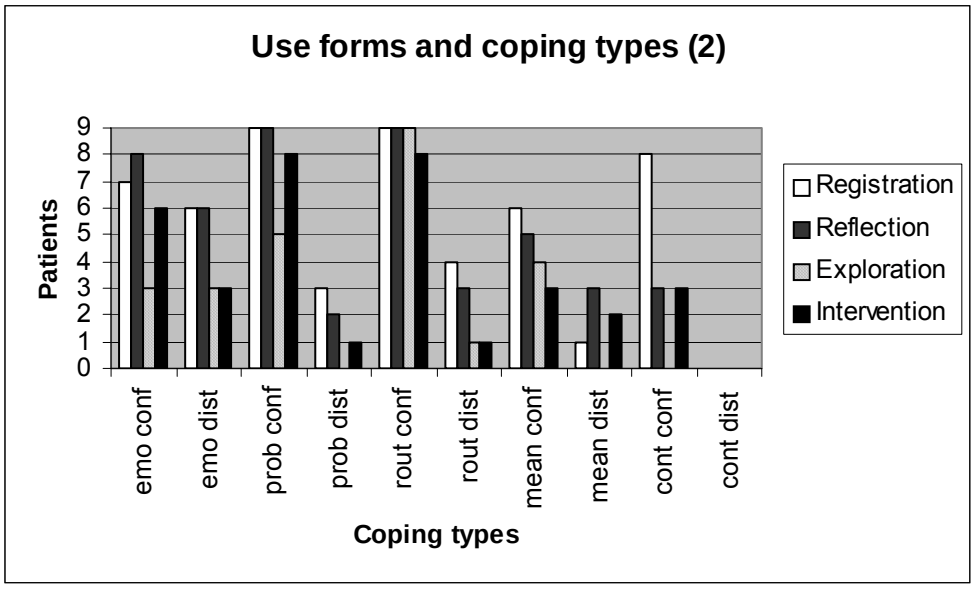

Fig. 5.3: The number of patient interviews coded by coping types and DiasNet use forms.

experienced having no motivation for self-care (employing emotion-focused distancive coping strategies instead). Also, Jens said that on an everyday basis the weekly periods of SMBG helped him morally to stay focused on his self-care. He explained, that normally when not taking SMBG he would tend to build up a *laizzes-faire* attitude to his self-care, but that the measurements would confront him with his condition to make him go back 'to scratch' every week. Bent expressed a similar experience. Nevertheless, like two other patients, Bent later stopped taking SMBG because of a lack of feedback from the clinicians, even though all three had been appreciating having to take more SMBG as a part of the project. Jens, having a more active attitude, began to send questions to the clinicians by mail after having registered his data, because then, he said, 'they would have to send me an answer.' To sum up, these examples show that in almost all patients the project initiated a long-term SMBG routine, but that for many patients surveillance was essential for keeping up this routine. Besides having to enter SMBG, it was also required to enter estimated data on intake of carbohydrates. Many patients expressed that this particular aspect of the project had been one of the most beneficial.

There is also a wide spread match between **registration** and **problem-focused confrontive coping** (found in all 9 patients), and for a variety of reasons. Per said that it gave him a feeling of security that in case of troubles he could just send a mail to his contact-person asking for advice by referring to the current data. In addition, this felt much easier to do, instead of having to 'disturb' the doctor by calling him on the phone. Furthermore, many patients experienced periods of intensive use of DiasNet (sometimes measuring SMBG for up to six days instead of three) as advised by the clinicians and as a part of a dramatic cut in the insulin regimen (up to 50%). Also, some patients experiencing periods of severe instability in their blood sugar level made agreements with the clinicians to intensify the registration in order to study the problem. Some patients also registered extra SMBG by their own initiative when being confused by their SMBG pattern, or in case of waking up at night and having to go to the toilet. Most of the patients did so to provide greater insight into their problem for the clinicians to find a solution, while a few did so in order to study the problem more deeply themselves. In addition, many patients said that the project had made them taking extra occasional SMBG to control their current situation in case of doubt.

Regarding the match between **reflection** and **routine-focused confrontive coping** this was also found in all 9 patient interviews. Most patients said that after having entered their data they would always check the simulation to see the difference between this and their own SMBG curve. Sometimes they would then study their data even further, mainly by

checking their IS (insulin sensitivity). Many patients had experienced periods of spending up to half an hour on a weekly basis studying their data. (This, however, could also include exploration, i.e., carrying out virtual experiments). This way, most patients expressed having learned a lot about, e.g., the concepts of counter-regulation and IS, the long-term effects of taking extra insulin and the importance of having patience with elevated blood sugar levels, the importance of balancing the intake of carbohydrates to the intake of insulin and the difference between various types of food, or taking SMBG before doing sports instead of only taking extra carbohydrates. It thus seems that DiasNet has initiated a lot of learning in the patients, and one way in which this was brought about seems to be by initiating thoughts on metabolic dynamics and everyday disease management. As an example, when I asked Morten whether he found it a big challenge to improve his metabolic control, he said:

> *Yes [barely audible]. It is. But then again, it is just everyday life. It is not something I tend to think about normally. I would say that the only time I consider this matter is when I sit down for about a quarter of an hour to half an hour and look at my data on the net [DiasNet]. And then again, one always has this question in the back of one's mind, but it is not something I tend to ponder over. (Morten)*

Also, Per was surprised about the amount of new knowledge he had acquired through using DiasNet. As an answer to my question about which advice he would give a young person just being diagnosed, he said:

> *I would say that they should take their blood sugars meticulously, and follow the rules about diet, and... if they have the chance of getting access to DiasNet, then to use it, because it is of great help. [eb: To learn about diabetes?] To learn about it. When I was diagnosed, I didn't know anything. This way they can learn about it much quicker. [..] And even though I have had it for so many years, I learned a lot last year! It may sound strange, but I really did. (Per)*

When reading this passage it is interesting to notice that Per does not seem to refer to the health professionals regarding the merits of DiasNet, even though he appreciated this contact very much. Similarly, while Richard said that he was happy about the enhanced contact with the clinicians due to the project, he did not care whether DiasNet was web-based or a stand-alone system. What he enjoyed the most was to check his own data once in a while and to make comparisons between periods of time. Two other participants, Morten and Karsten, also expressed their indifference to whether DiasNet was a web-based synchronic surveillance system or not. Hence, what is also highly interesting about this use form is that it, contrary to registration, seems to highlight the patient's interest in being actively relating to his diabetes, instead merely relying on the health pro-

fessionals. And as discussed above about the motivational aspects of having to take SMBG on a regular basis, many patients expressed that the mere view of their own data on the screen was also motivating to focus on self-care. Hence, Connie said that she could sometimes have unpleasant surprises by watching 'my curve' and wanting it to be lower, and Karsten said that his data could sometimes have the effect of a bogey. For the same reason, Morten said that he had always known about the importance of SMBG, but that it was only now that he had actually started doing it.

Finally, concerning the match between **reflection** and **problem-focused confrontive coping** (also found in 9 patient interviews), most patients had tried to analyse their data in case of highly elevated blood sugar levels to find out whether it was due to counter-regulation. Also, many patients had tried to think up hypotheseses and strategies to enhance their metabolic control, either directly using DiasNet, or indirectly in terms of decision making being founded on knowledge acquired through the use of DiasNet. Interestingly, there were many examples of strategies which the clinicians found surprising, if not dubious, but which the patients themselves were convinced about, including taking extra insulin before doing sports (because of hyperglycaemia provoked by the exercise, something which the clinicians could not explain); taking extra insulin when having a hypo (because the patient in question knew that he would tend to eat too much); as well as having a low IS and, consequently, wanting to try out taking a great deal more insulin than recommended by the clinicians. Also, during an interview while looking through the participant's data in DiasNet, the participant became aware of 'a good period' some months before. This was during a period of time in which he was experimenting a lot in collaboration with the clinicians in order to find the right strategy, and therefore the regimen had been changed since then, unfortunately with no good results. When seeing the good period again in the data, he therefore promised himself to contact the clinicians to discuss this issue with them.

Concerning other coping types characterising the various use forms, **registration** also has a considerable ratio of contact-focused confrontive coping (a match found in 8 patient interviews), again indicating that most patients appreciate being in contact with the clinicians by way of entering data and receiving feedback.

> *It is lovely to have that contact with the hospital once a week, it gives a feeling of security. (Connie)*

This supervisional interactivity does not seem to be depending on constant feedback from the clinicians. Instead, surveillance seems to be the essential aspect, since most patients trusted the clinicians to react in cases of alarming home monitoring data. This surveillance encouraged some of

the patients to break away from a strict routine. At the other hand, due to experiences of a lack of regular feedback, many patients also built up a lot of frustrations about this. And instead of contacting the clinicians to put forward their needs, some patients gave up on the clinicians, which in at least three cases contributed to their decision to stop entering data. Other patients were busy in trying to excuse the health professionals by referring to their tight schedule. Reactions like these were coded as emotion-focused distancive coping, and this was found in 6 patients in relation to registration. What is more, this use form also had the highest ratio of routine-focused distancive coping (4 patients). As an example, one patient (Karsten) said that if he was told in the beginning that the clinicians would not send any regular feedback, he would have taken more initiative to look into his own data, instead of 'passing on the monkey' (Danish expression) to the clinicians. It can thus be observed that surveillance not in every case will encourage a patient to become an active instead of a passive recipient of heath care.

Concerning **reflection**, this use form seems particularly related to emotion-focused confrontive coping, apart from routine-focused and problem-focused confrontive coping (8 patients). In many cases, this had to do with getting a feeling of confirmation and moral support by studying own data in DiasNet on a regular basis. To provide a few examples: During the project, Jens became aware of the concept of insulin sensitivity (IS) and its relation to doing physical exercises. He therefore started jogging two or three times a week, and was happy to see the effect on his IS within DiasNet. Likewise, Bjarne expressed that he would have appreciated having access to the other patients' data in DiasNet (and perhaps also that the other patients could follow his data), as he would then feel inspired to do his best. Furthermore, while Jens was having difficulties in combating high blood sugar levels in the morning, seeing his own SMBG curve being close to the simulation curve sometimes comforted him, even though both were elevated, since in his view matching the simulation was an ideal. Likewise, Connie, after being taken by surprise by a severe hypoglycaemia, was comforted to see that 'it', the simulation, did not foresee this development either. Also, Per expressed a comforting feeling of 'double control' when consulting DiasNet and seeing that 'it' confirmed his own thoughts on what to do in a given situation.

In addition to the above examples, many patients also expressed positive feelings about DiasNet as a tool, i.e., about the visualization facilities of DiasNet, which the patients felt was essential in finding patterns in their SMBG. And as a final example, being of particular interest concerning empowerment, Karsten experienced feelings of comfort in spite of not experiencing any improvements during the project. The reason was that,

since he had gathered so many data during the project, he now felt that his position was much stronger when disagreeing with the clinicians.

The use form **exploration**, in particular, is dominated by routine-focused confrontive coping (9 patients). As this indicates, all of the patients would once in a while make use of the exploration facilities to experiment with their data for up to half an hour after having entered their data. This happened as a part of the routine of using DiasNet especially after the midway meeting where the patients had been further introduced to the exploration facilities. The patients did so in order to 'play and learn' and most patients said that in this way DiasNet proved to be a fine learning tool. A focal example, Hans was surprised to realize the importance of timing regarding insulin injections. This experience later influenced his disease management. Another interesting example is Bjarne, who said:

> *Well, I don't find it [DiasNet] all that exciting to look at, but.. I do have tried to sit down to mess about with it [the data] to see .. if one does this and this, then what happens? That is highly interesting to sit and look at. But I just don't think that I really managed. [eb: To actually get it down (the blood glucose)?] Yes, in real life I couldn't manage, but I could easily manage on the computer. (Bjarne)*

Bjarne was one of the three patients who expressed a strategy of such use, which was coded as a dictum saying 'explore to learn!', i.e., to do explorations as a part of the project, much like doing homework, to learn as much as possible. What I find particularly interesting in the above citation, however, is that it seems that Bjarne acquired more than mere knowledge from this effort. He found it 'interesting' that he was able to manage his diabetes virtually, while not being able to manage in real-life. In the context of how exciting he finds the interface of DiasNet, my interpretation is that he found it exciting to do explorations, and I relate this to his experience of being able to manage something virtually, which he could not manage in real-life. Hence, apart from routine-focused coping, I also coded this passage as emotion-focused confrontive coping. This way, I take it as an example of how DiasNet can promote self-care motivation by enhancing self-confidence, much like a coach saying 'you can do it!'

Finally, the use form **intervention** is primarily related to problem-focused confrontive coping (8 patients). Only three patients reported having used DiasNet directly in planning. Hence, most cases of this use form are examples of improved decision-making in which DiasNet is indirectly related, due to knowledge or experiences acquired through the use of DiasNet. For instance, during the project Connie, a middle-aged woman, went from emotion-focused distancive behaviour to problem-focused confrontive coping in cases of elevated blood sugars, and she claims that the use of DiasNet helped her in developing this new approach to not be-

ing afraid of taking extra insulin. For a single patient, intervention became the primary use form in combination with problem-focused confrontive coping. This example is particularly interesting. Being in his late thirties and already suffering from a number of serious late complications related to years of ill-stabilised diabetes, Bent stopped entering data to the system some time after the mid-way meeting, since he understood that the clinicians did not look at his data anyway. And while he had appreciated the new habit of measuring SMBG on a regular basis, which was a necessity to be part of the project, he soon after went back to his old habit of only taking SMBG when having feelings of hyperglycaemia. Nevertheless, in such cases he began to consult DiasNet in order to avoid taking too much insulin. As he said, 'it is more fun to play with that one [DiasNet] than to play with one's own body!' This happened a handful of times, he claimed, however, without saving the data he entered to carry out the simulations. He said that he appreciated this opportunity and that he would not like the system to be closed down. This way, he said, he would not have to call the hospital when being in trouble. He further explained that he did not like being in contact with the clinicians, since he feared facing a lot of criticism because of his data. I find this example particularly interesting, since carrying out a simulation in DiasNet in fact is a problem-solving action being oriented toward stabilising the blood sugar level, i.e., a case of problem-focused confrontive coping. While at the same time, it seems to be sustaining a coping process, which also includes a lot of emotion-focused distancive coping strategies, such as neglectance, withdrawal, and blaming others. Furthermore, while Bent indisputably has improved his decision making, this may be a kind of empowerment that doctor's fear, since in this case it seems to add to the distance between the patient and the health professionals. A very similar story was found in one other patient, Karsten, the main difference being that at the time of the interview he was planning to take up registration once again, however, only for his own use, and to carry out intervention experiments building on a hypothesis (concerning his high IS) being contrary to the advice he was given by the health professionals.

In the above analysis, a single coping type among the most common coping types, meaning-focused coping, has not yet been mentioned. However, it does not seem to characterise any use form in particular. Nevertheless, in most patients it is related to registration. As an example, Jens said:

> *Before I reduce all this about measuring blood sugar and reporting my data, then I want my data to be almost perfect every time. If they start to be perfect during three or four weeks, then one can say 'now, it really works', 'now, it is in control!' Then, clearly, one*

> *could begin to stretch it a bit, because then one has found the balance. (Jens)*

This is an example of Jens' motivating thoughts sustaining the long-term use of DiasNet in order to 'find the balance'. Later, he expressed a similar goal by drawing how he would like his SMBG curves to look on the screen. Hence, both these examples show how DiasNet has become an integrated part of the patient's view on his disease management, the first in terms of registration, the latter in terms of reflection. As a similar example, Hans, being a retired math teacher, gave the following answer to my question whether he found it difficult to keep on doing the extra work of registering SMBG in order to use DiasNet:

> *I do not think of it as extra work. [..] And then again, it doesn't take too much time anyway. Four daily measurements, that takes two minutes in total a day. An then to enter the data ... if we count the minutes being spent on one's diabetes, while one is not able to do other things at the same time, then it is .. less than an hour a week. Including injections, controlling one's diet, blood sugar measurements, and playing with the system [DiasNet]. And there are 168 hours to spend. That is not.. That is less than 0,75%! (Hans)*

Having thus characterised the health behaviour being related to the four use forms, I will now describe how the analysis of the use forms help in analysing the use of DiasNet in terms of adoption and empowerment.

5.1.2 Use forms, adoption and empowerment

In this part of the analysis, I have concentrated on the concept of use forms as various approaches to DiasNet in terms of various goals, i.e., in terms of a variety of actions within health activity mediated by DiasNet. A set of four different use forms were identified through open coding, and the material was then analysed statistically, firstly, to study the relative weight of each use form in the general use of DiasNet, and secondly, to study the relation between each use form and coping types. When discussing adoption and empowerment I will mainly refer to the identification of the various phenomena found in the material, but also refer to the findings based on the statistical analysis.

Concerning the identification of the use forms, the resulting set was different from my expectations, mainly concerning the use form reflection, i.e., using DiasNet as a mirror. Both the mere existence of this use form and the heavy distribution of it in the material are signs of adoption, since it shows that the patients to a large extent have integrated DiasNet into an unanticipated type of goal directed actions. In addition, the distribution of exploration and intervention also shows that the patients have developed use patterns, which to a large extent exceeds the obligatory registration.

What is more, the identified use forms exceeding the obligatory use form have a clear match with Roter's empowerment concepts inspired by Freire. Also, particularly the use form reflection having emerged from the patients' use may thus complement the medico-centric perspective of the above coping analysis with a patient-centric perspective as well. Hence, the adoption of DiasNet in terms of the non-obligatory use forms also shows signs of supporting empowerment.

Concerning coping types and the mapping between these codes and use form codes in the material, it was observed that each use form is related to many different coping types. This indicates that the patients have found the various use forms useful in many different ways. Again, this is taken as a sign of adoption. At the same time it appeared that all use forms were dominated by two coping types, which are topping the list of signs of empowerment concerning coping (cf. chapter 4), i.e., routine-focused and problem-focused confrontive coping.

Focusing on the two most common use forms, registration and integration, many examples came up which can be considered signs of adoption and empowerment. Thus, registration and reflection seems to have initiated a long-term SMBG routine as well as extra occasional SMBG in almost all patients, and in the literature it is broadly accepted that a key to obtaining better metabolic control is for the patient to carry out SMBG on a regular basis (Guerci et al., 2003; Franciosi et al., 2001). Furthermore, both use forms seem to initiate more focus on self-care, both in terms of routine-focused confrontive coping and problem-focused confrontive coping. As an aspect of this, besides having to register SMBG, the patients were also required to enter estimated data on intake of carbohydrates, and many expressed that this particular aspect of the project had been one of the most beneficial. However for most patients, surveillance and the collaboration with the clinicians was important for keeping up this activity.

Nevertheless, some of these patients later were motivated to keep on registering data for their own reflection. At least three patients thus said that they were indifferent whether the project would be closed down if they could still have access to DiasNet, or use it as a stand-alone system implemented on their PC. As a motivational factor, all patients expressed having learned a lot by analysing their own data. Relating to their own data as visualised on the screen and with the analytical facilities within DiasNet seems to have initiated many thoughts on metabolic dynamics and everyday disease management, as well as given inspiration to a search for solutions. (A part of this was also due to the exploration facilities). Thus, there are many examples of own hypotheses and strategies, often in opposition to the clinicians.

In addition, emotion-focused confrontive coping was also characterising reflection, mostly due to feelings of confirmation and moral support by studying own data in DiasNet on a regular basis. Also, one patient who was disagreeing with the clinicians on their treatment strategies felt that his position in this debate was made stronger through gathering so many data during the project. Finally, meaning-focused coping was related to registration to some extent pointing to examples of self-care motivating thoughts in which the use of DiasNet was integrated. These observations are all taken as further indications concerning adoption of DiasNet as well as empowerment support through this adoption.

Regarding the third use form exploration, this was characterised by routine-focused confrontive coping, which is taken as a sign of adoption. Furthermore, one patient reported having realized on his own the importance of timing regarding insulin injections. This later made him change his disease management routines. This is taken as an example of empowerment *par excellence*.

Concerning the fourth use form, intervention, only three patients reported having used DiasNet directly in planning. Thus, it seems that DiasNet was not widely adopted as a decision support system among the patients. However, in 8 patients examples were found of decision making being influenced by knowledge or experiences acquired through the use of DiasNet. This may be taken as an indication of indirect adoption of this use form. And since the intervention use form was primarily related to problem-focused confrontive coping, it is also taken as an indication of patient empowerment. Furthermore, it was discussed whether a case of problem-focused confrontive coping with relation to intervention was supporting empowerment, since in this case (Bent) it seemed to add to the distance between the patient and the health professionals. A coping process has to be observed as a complex whole. However, this does not mean that it is impossible to analyse the various aspects of it. Likewise, it would hardly be fair to judge every aspect of a coping process only by looking at the overall pattern. Hence, regarding the case of Bent, I believe that any instance of problem-focused confrontive coping can be considered small steps in the right direction, even though in this case it may seem to deepen his main problem of not staying in contact with the health professionals.

At the other hand, it was also found that one use form in particular, registration, was also characterised by coping types, which are not considered signs of empowerment, namely emotion-focused and problem-focused distancive coping. But when looking into the material being coded as emotion-focused distancive coping it appeared that in many cases this was related to frustrations concerning a lack of feedback from the clini-

cians. As for problem-focused distancive coping, it was observed that some patients may tend to act as passive recipients of health care, and that this pattern may not be changed fundamentally just by having to enter SMBG into a surveillance system like DiasNet.

5.2 DiasNet-related artefacts

After having described various uses of DiasNet, I will now concentrate on the artefacts, which I have identified in CDDM. These were identified in accordance to my discussion of artefact types above (cf. chapter 3), i.e., What, How, Why, and Where-to artefacts and their relation to levels of learning as well as levels of reflection on activity aspects. For each level, I will present the artefacts by listing the identified sub-categories and discuss their relation to the actual level (cf. appendix E concerning What artefacts, as well as the lists below concerning How, Why, and Where-to artefacts). I will then discuss the issues of adoption and empowerment by referring to the distribution of the sub-categories in the patient interviews. Concerning What artefacts, I will discuss these issues by taking account of use forms and coping types. Such meticulous analysis is only carried out concerning What artefacts, since the primary artefacts of DiasNet (and related What artefacts) are the focus of this analysis. As for the higher-level artefacts, these are seen as aspects of DiasNet's interface, which the participants have had to acquire or develop as a part of using DiasNet. Hence, the mere identification of such artefacts may suffice to illuminate the patients' adoption of DiasNet, and empowerment will be discussed with reference to the implied learning level. As for the latter issue, this analysis implies a conception of patient learning, which entails many more aspects than merely acquiring basic disease management skills. Hence, this discussion will emphasize a patient-centric as opposed to a traditional medico-centric compliance-based approach.

5.2.1 What artefacts in CDDM

Due to the nature of the semi-structured interviews, I did not go through the DiasNet interface in any systematic manner in order to obtain the participants' views on it. Instead, the identification of What artefacts is in most cases inferred from the more informal talk about the participants' experiences concerning CDDM. I include artefacts, which are essentially related to the use of DiasNet as expressed by the participants, e.g., mails (to the clinicians) and the use of SMBG meters. In the appendix is found an overview of these artefacts together with information on the number of patient interviews and passages in which they are mentioned (appendix E). Furthermore, I also provide information on the number of patient interviews a certain artefact is found in relation to combinations of coping types and use forms. This was not done merely by queries as in the ana-

lytical work above. Instead, I analysed each passage in question to count manually the number of patient interviews in which the various combinations of use forms and coping types were found in relation to every specific artefact.

Regarding adoption, not surprisingly it is the Input dialogue (the lowest half of the figure in appendix E.1), which is mentioned most times and only in relation to registration. At the same time, it is mentioned by most patients in relation to many different coping types. Both indications (being the number of times the Input dialogue is mentioned and the number of various coping types in relation to which it is mentioned) are signs of adoption. Concerning empowerment, the Input dialogue is only mentioned in relation to registration, i.e., an obligatory use form. Meanwhile, it is mostly related to all of the confrontive coping forms, indicating empowerment. At the other hand, it is also to some extent related to emotion-focused and problem-focused distancive coping.

Together with the Input dialogue, two other artefacts seem to be highly adopted, as they are also mentioned very often and in relation to a lot of coping types, namely SMBG and mail. Mail is only mentioned in relation to registration, indicating the importance of communicating with the clinicians – mostly as contact-focused and problem-focused confrontive coping. The use of this artefact is a further sign of the adoption of the Input dialogue, while in terms of empowerment it is heavily supporting problem-focused confrontive coping. As for SMBG, this is mentioned in relation to intervention as well, indicating that it has been integrated into more than the obligatory use (registration), which is taken as a sign of adoption. Concerning empowerment, it seems that SMBG is mostly related to the obligatory use form, but at the same time it seems to be heavily related to problem-focused and routine-focused coping in relation to intervention.

Carbohydrate (CH) estimates are also mentioned, but not so often. Still, it is related to a lot of different use forms and coping types, which indicates adoption. Concerning empowerment, CH only seems to be related to the two coping types, which are taken as the focal indicators of empowerment (routine-focused and problem-focused confrontive coping), and what is more, it mostly seems to be related to non-obligatory use forms (intervention and reflection).

Finally, one patient (Morten) explained how he sometimes would include small reminders into the file names when entering his data. Like many other participants, Morten said that he would have appreciated a facility within DiasNet to write comments about his current situation to explain his data. But unlike the other patients, he developed a method to have his

comments included. Hence, even though this artefact is only mentioned once, it is taken as a sign of adoption. Furthermore, the mere fact that a patient developed this artefact[19], and in addition, that it is related to problem-focused confrontive coping, are taken as signs of empowerment.

Concerning the upper half of the screen, the Data dialogue (appendix E.1), two artefacts are mentioned, being the SMBG graph (black and linear, connecting red dots) and the blood glucose simulation (red curve). The first one is only mentioned in relation to reflection, while the other also is related to intervention. They are not, however, mentioned in relation to a high number of coping types. But in themselves, both use forms are signs of adoption. Also, concerning empowerment, both artefacts are only related to non-obligatory use forms as well as confrontive coping types.

As for the next screen (appendix E.2), what has changed is the lower half, which is here presenting the Future dialogue. This dialogue is used either for seeing the effect of making virtual adjustments to the data, or for carrying out automatic optimisations. It seems that the Future dialogue is mentioned quite often and by most patients, indicating a high degree of adoption. Furthermore, the amount of various use forms and coping types are also indicating adoption. Concerning empowerment, the Future dialogue is only mentioned in relation to non-obligatory use forms as well as the focal coping types (routine- and problem-focused confrontive coping).

In relation to the Future dialogue, a few other artefacts are also mentioned (Risk, Ratio, and Two horizontal lines), however only by a single patient (Jens). This indicates that these artefacts are not adopted in general. However, both regarding use forms (reflection) and coping types (problem- and emotion-focused confrontive coping) they seem to support empowerment in this particular patient.

Concerning the third screen (appendix E.3), the 'Advanced' dialogue being activated, this is only mentioned in three patient interviews. It thus seems that the facilities to analyse insulin sensitivity is not well adopted generally. However, when this facility is mentioned it is mostly in relation to a non-obligatory use form (reflection) and various confrontive coping types (problem-focused, emotion-focused, and routine-focused), which all are taken as signs of empowerment.

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[19] The process of devising the method to produce this artefact exemplifies a reflection on means due to a breakdown situation (a mal-functioning interface), instead of keeping a focus on the object. Therefore, this process exemplifies learning I, or a secondary action, while the products of using this method, the actual reminders, function as What artefacts, which are devised and used in primary actions.

To sum up, regarding adoption, three dialogues of the DiasNet interface seem to be adopted to varying degree. The Input dialogue together with the use of SMBG and mail were adopted to a large extent for registration. Also, the SMBG curve and simulation was widely adopted for reflection. And what is more, this adoption was exceeding the obligatory use of DiasNet. Also, the Future dialogue was adopted by most patients, while the Advanced dialogue, which is used to analyse IS, was not. But still, it was adopted to a considerable extent by the few patients using it.

Concerning empowerment, while the Input dialogue – naturally – is mostly related to the obligatory use form, registration, the others are mostly related to non-obligatory use forms. What is more, all of the What artefacts are mostly related to confrontive coping and mostly the two focal coping types concerning empowerment. On the other hand, a few of the What artefacts (the Input dialogue, SMBG and the use of mail) are also to some extent related to emotion-focused distancive and problem-focused distancive coping, which are not taken as signs of empowerment.

5.2.2 How artefacts in CDDM

How artefacts were identified in the material in relation to secondary actions reflecting on means and conditions, such as instructions and routines, as well as patient views on the use of DiasNet and related artefacts. In addition, in Learning I there is a change in punctuation where the subject leaps from merely noticing the actual conditions to becoming aware of the context it is facing (to learn what must be done in such a context). Hence, the acquisition of new concepts concerning the use of DiasNet is also included in case they do not seem to be the product of a patient deliberately exploring the nature of a given context. The latter would qualify as Leaning II (‘learning to learn new contexts’). Likewise, new routines being devised by the patients themselves are included in case they seem to be the product of ‘action response’ (qualifying as Leaning I), and not ‘theory response’, which qualifies as Learning II. In short, How artefacts are identified in terms of three aspects:

- Instructions and new routines, including ‘action response’;
- patient views on the use of DiasNet and related artefacts;
- new concepts/ contexts.

The following list of How artefacts are ranked according to the distribution in the patient interviews (primarily, in terms of the number of patient interviews, secondarily, the amount of passages). Each sub-category is in bold typing, while italics are used for ‘in vivo codes’ (patient citations). Examples of the specific codes within the sub-category are given in the parentheses:

Thoughts on communicating with the clinicians via DiasNet and mail (9 pts/40 pass: surveillance gives a feeling of security; more easy to ask for advice; to walk on a line with no safety net; DiasNet is mainly the doctors' tool; receiving coaching comments from the clinicians by mail);

SMBG routines (9/32: taking more occasional SMBG; it gives a good feeling to do SMBG; it is unpleasant to do SMBG, but has become a habit; SMBG before sports activities);

playing with data/ testing adjustment ideas virtually (8/27);

mirror (using DiasNet as mirror) relating to the simulation as an ideal (8/17);

mirror: looking into own data (7/13: things are not as intended; *SMBG graph is sometimes surprisingly elevated*; *it is now in 'black and white' how bad things are*; rewarding to notice improvements; to include reminders in file name);

DiasNet helps in gaining control (7/13: easier to stabilise oneself; DiasNet gives new 'backbone-reflexes'; correctly adjusted insulin gives inner peace);

carbohydrate estimations (6/15);

three-day routine of home monitoring and DiasNet use (6/11);

DiasNet is a fine visualisation tool (6/11);

The simulation is not real life (6/8);

agreements with the clinicians on DiasNet activity (5/15);

mirror: noticing other stabilisation indicators (5/14);

decision support in case of hypers/ hypos (3/6);

DiasNet strengthen patient's position in discussions with the clinicians (3/5: e.g., wants to discuss a 'good period' with the clinicians);

decision support (using DiasNet as decision support system) in planning (3/3);

clinicians' methods for obtaining stabilisation (5/10: *be careful not to take too much insulin when experiencing hyperglycaemia*);

own methods for obtaining stabilisation (3/6: dared taking extra insulin before sports activities; SMBG before playing football instead of extra carbohydrates; a little insulin before running to enhance jogging experiences; taking extra insulin when having a hypo because of excessive hunger);

dictum: *explore to learn!* (3/3);

Yet, I can manage virtually (2/3);

taking a holiday from DiasNet once in a while (1/1);

one cannot expect results right away (1/1).

Concerning adoption, the diversity of categories of How artefacts, and that many of them are of the participants' own making, are taken as signs of the amount of secondary actions, which the participants have been carrying out to integrate DiasNet into their primary health actions. This is taken as a sign of a considerable adoption of DiasNet as a system, while, at the same time, the analysis shows the adoption of How artefacts in themselves. It is noticed that the two largest sub-groups both being mentioned by all participants have to do with the relationship to the health professionals, and SMBG routines. This could mean that among the nine patients the system itself (in a 'narrow sense') was not the most important factor concerning the adoption of DiasNet. Instead, it seems that it was adopted as a pathway to other more important factors being parts of the system in a broader sense: the promise of enhanced contact with the clinicians, and the incentive to have an SMBG routine. In a more narrow sense, what seem to have contributed the most to adoption are the facilities to play with own data and to use DiasNet as a mirror.

Concerning empowerment, again, the long list of various How artefacts may illustrate that a considerable amount of Learning I has been taking place among the participants. Firstly, some of this learning had the form of following new instructions and taking up new routines (including 'action response'). Concerning new instructions, the list includes doing carbohydrate estimations, the three-day routine and other agreements on DiasNet use, as well as clinicians' methods for obtaining stabilisation, which all are mentioned by five to six patients. It is noticed that this list solely consists of instructions given by the clinicians. This is not the case concerning most of the new routines, having to do with SMBG (e.g., taking more occasional SMBG), and using DiasNet as a mirror, as well as using DiasNet as a decision support system. The participants took up these routines by their own initiative. And what is more, two of these routines are mentioned more often than the clinicians' instructions. This could indicate that such new routines contribute as much to patient empowerment than the instructions from the clinicians, perhaps even more so, especially if the concept of empowerment is connected to a patient-centric approach. Furthermore, 'action response' was found to a considerable extent. As an example, as Morten explained how he developed his method of taking extra insulin before sports activities, he said '*I just had to do something!*' In other words, he was not relying on any model or a

theory to explain why this would work, as in theory response. Also, using the Future dialogue to try out various regimens (the sub-category 'playing with data and testing adjustment ideas') exemplifies action response, as it resembles experiments of balancing blocks, while not necessarily relying on any hypotheses (cf. the example discussed in Chapter 3). This was found in no less than eight patients. Similar examples are found among the sub-categories 'Own methods' and 'Dictum: Explore to learn!', which were both found in three patients. Such 'tinkering' ('action response' without a hypothesis) may indicate a lack of knowledge, both about how to handle a problem, and how to think about the problem. Still, in my view, such examples primarily indicate an interest in trying to find the right means to solve a problem. I therefore regard examples of action response as signs of empowerment – however, not of the same rank as theory response.

Secondly, some of the How artefacts had to do with patient views on the use of DiasNet and related artefacts. This list includes the experiences that DiasNet helps in gaining control, and that it is a fine visualisation tool, both mentioned by most patients, while three participants expressed that it strengthens their position in discussions with the clinicians. These are all taken as clear indications of patient empowerment due to DiasNet, especially from a patient-centric view.

Thirdly, some of the How artefacts had to do with understanding new concepts concerning the context of DiasNet use. As many as five participants expressed having noticed on their own a number of stabilisation factors, as well as context markers of pending hypo- or hyperglycaemia, such as the importance of timing, the differences in the need of insulin before and after work, a relation between nervousness and high blood sugar levels, and excessive intake of carbohydrates by eating a favourite dish. Such examples are taken as clear indications of empowerment. Furthermore, a variety of views were observed concerning the simulation: On the one hand, it was seen as an ideal, and here, in many cases a match between the simulation and their SMBG or their expectations seemed to enhance their self-confidence. On the other, that the simulation was not realistic. In fact, both views were found within the same interview (Jens). Likewise, the participants' thoughts on the communication with the clinicians also illustrate their ambiguous views on this aspect of the DiasNet use. In my view, such confusion can hardly be conceived of as a contribution to patient empowerment, even though these How artefacts can be considered instances of Learning I. Instead, such cases of ambiguity may call for learning of a higher level. Reflecting on this problem, that it may not be possible in any case to say that Learning I is supporting patient empowerment, one good reason, of course, is that misunderstood con-

cepts do not empower anyone. On further reflections, it may be the case that some concepts are of a kind, which takes learning of a higher level than Learning I in order to be understood, or administered, correctly, e.g., a concept denoting a way of thinking, instead of merely denoting a certain routine.

5.2.3 Why artefacts in CDDM

The Why artefacts are identified in accordance with the discussion in chapter 3 and thus relate to the concept of Learning II in terms of theory response, and in terms of changes of punctuation when exploring the nature of a given context in light of a larger whole of contexts, as well as when reflecting on goals instead of merely focusing on means and conditions. The ranked list of identified Why artefacts is as follows:

Counter-regulation as explanation (8/20);

clarified/ altered disease management goals (7/29: e.g., to write questions to clinicians to get feedback on data; to collect data and to watch the effect; DiasNet is only for normal/ ideal days; the data profiles have to reflect my every day life; seeing the point in DiasNet and making it a part of every day routines; the more data the better; clarified and more realistic – lower – ambition);

own observations about disease management factors (7/28: e.g., constantly having high ambitions may cause tedium; theory about high blood sugars due to nervousness during football matches; *the simulation is not accurate because of hormones*; becoming more aware of self-care outside the routine; *rules of thumb do not work*);

theory testing in real life (6/12: counter-regulation hypothesis is sought verified; hypothesis concerning own low IS; hypothesis concerning less insulin before work).

The mere existence of all four sub-categories as well as their wide spread distribution in the material are taken as signs of adoption, since they are the product of non-obligatory tertiary actions, which the patients have been carrying out to integrate the use of DiasNet into their primary health actions, either directly or indirectly. It is noticed, that except from the hypothesis of counter-regulation the Why artefacts are of the participants' own making. What is more, they relate to the patients' every day life, and in addition, one of the sub-categories has to do with the way seven of the nine patients have clarified or altered their disease management goals. Again, these results of the analysis are taken as signs a considerable adoption of DiasNet as a system. At the same time, the analysis shows the adoption of Why artefacts in themselves, the adoption of which may also

be interpreted as signs of empowerment, especially when seen from a patient-centric perspective. This requires further explanation in all four cases.

Firstly, examples of theory response are particularly clear regarding the sub-category 'theory testing in real life'. As an example, one patient (Karsten) was convinced that his stabilisation problems were due to very low insulin sensitivity – something he was made aware of by studying his data in DiasNet. And consequently, he was determined to carry out an experiment of increasing his intake of insulin considerably, contrary to the clinicians' recommendations. In such a case, the patient's experiment will be guided by an idea, instead of merely being tinkering, as in action response. Thus, focusing on such an experiment is to be oriented toward a theory, i.e., temporarily to focus on a goal (to test a hypothesis) as a part of an overall activity being oriented toward obtaining metabolic control. While some clinicians may not agree to this experiment, as an increase of the insulin level is regarded as a less optimal disease management strategy, this misses the point in terms of supporting patient empowerment understood as a learning process of the patient.

Secondly, regarding the counter-regulation hypothesis, this was presented to the participants as a part of the diabetes school. One may therefore question whether this ought to be considered an instance of theory response since it is not a product of the participants' own creative thinking. Also, one could argue that the concept of counter-regulation is merely to be conceived of as a type of context, which has been pointed out to the patients in terms of certain context markers, and thus may be considered a case of Learning I. However, I would argue that there is a change in punctuation between following a situation specific prescription (e.g., *do not take extra insulin in case of a highly elevated blood sugar level following a hypoglycaemia*), and understanding a theory about the metabolic dynamics (i.e., the release of counter-regulation hormones) resulting in a type of situation in which the prescription applies. What is more, I would claim that the kind of interest that is required to understand such a model, i.e., an interest in understanding the underlying factors of an everyday phenomenon, is no different from the interest behind other instances of theory response in the sense that it is directed towards a theory as its 'object'. In other words, to understand a theory like the Somogyi effect, or to be interested in understanding it in the first place, carries the same feature of creative thinking as developing it, i.e., an ability of 'learning to learn'. To convey such interest and to support such understanding is considered empowerment support of a high rank. The patient is being invited into the clinicians' way of thinking, instead of only being given the results in terms of a certain instruction, situation by situation. In other words, the

patient is not approached as an object to be manipulated to display a certain behaviour determined by the clinicians beforehand, but instead as a subject, which, potentially, could learn to become independent of the clinicians in determining situations and appropriate behaviour.

Thirdly, concerning altered goals, one example is writing questions to the clinicians in order to initiate feedback from them. I consider this strategy a result of a change of punctuation from merely observing a single context to seeing a pattern of various contexts. The participant (Jens) seems to relate to the pattern of the interplay between himself and the clinicians during various specific situations in which the clinicians sometimes send him feedback and sometimes not. The patient being this active and creative in trying to get feedback on his data (goal) motivated as he is by his interest of improving his disease management in collaboration with the clinicians (motive) are all signs of a highly empowered patient. Hence, I regard this as reflecting on a frustrated goal and to develop new means to obtain it anyway, in order to move on in Jens' overall 'team work' activity of improving his stabilisation together with the clinicians – instead of merely being frustrated in this team work activity as a whole, as most of the other patients felt.

Finally, concerning the patients' own observations, a nice example is the idea that constantly having high ambitions may cause tedium. Hence, in the long run some patients considered it beneficial in terms of metabolic control to cut down on disease management ambitions on a temporary basis. Even though this may be seen as a sub-optimal disease management strategy, it is taken as signs of patient empowerment of a high rank. It is a clear example of a change of punctuation, as these patients would view various periods as being parts of a whole. It is also an example of employing a hypothesis to explain an aspect of this whole in order not to be caught up in a pattern of dysfunctional disease management. Hence, like the example above, the idea is a sign of creative thinking of active and motivated patients.

To sum up concerning patient empowerment, I regard the list of Why artefacts – being parts of the DiasNet interface – as signs of learning on a higher level than the How artefacts, while instantiating a patient-centric approach in terms of creative thinking of active and motivated patients.

5.2.4 Where-to artefacts in CDDM

Following to the discussion earlier on the highest learning level (Chapter 3), three groups of Where-to artefacts were identified as follows:

Visions about life style changes related to DiasNet (9/57: Self manipulation for the purpose of focusing on self-care);

Visions about altered relationship to the clinicians (9/25: From dependency to independency; from a passive approach of 'passing on the monkey to the clinicians' to taking up a more active approach);

New codices (*I am a team player*; *it's important to be able to say 'I did my best'*) (1/2).

On the issue of adoption, these artefacts are not required for the obligatory use of DiasNet. Instead, they are the product of the participants' active engagement in integrating the use of DiasNet into their health activity. Hence, their mere existence and their wide spread distribution (in all nine patients), as well as their make-up (visions about profound changes of attitude to self-care), are all taken as clear signs of adoption of DiasNet. While DiasNet is the primary focus of this analysis, it should also be noticed the kind of Where-to artefact which have been adopted during its use. As described earlier (Chapter 2), the underlying agenda of the Diabetes project was to encourage self-care in terms of a more active, collaborative, and, in a future perspective, independent way of relating to diabetes and the clinicians. This agenda seems to have been adopted to a high degree.

Concerning the issue of empowerment, all the patients discuss the use of DiasNet in a way that is coded as self-manipulation for the purpose of focusing on self-care, or as a way to alter the relationship to the clinicians. For instance, many patients relate to DiasNet as a motivating reward for taking SMBG. This phenomenon represents a change of punctuation compared to the How artefacts related to the mere methods of employing DiasNet use forms. Hence, in this respect this equalises Learning II and could thus be conceived of as a Why artefact. However, I will argue that there is more to it than this, since I interpret such strategies as a deliberate way of contextualising oneself in order to change a certain reluctance to take SMBG, or to stay focused on self-care. In this respect, the patients may employ DiasNet as a part of an environment they device deliberately in order to change a pattern of behaviour (a habit), or a pattern of contextualisation (an attitude). And since these patterns are results of Learning II, the deliberate and long-term endeavour to change them, in my view, is a case of Learning III.

It may seem dramatic that all nine patients are displaying features of the highest learning level this way. But then again, they may not succeed in actually integrating this learning in the long run, i.e., that the subjects would succeed in integrating the new contextualisation patterns to sustain long-term effects. Again, surveillance seems to be an essential part of an environment, which helps to keep focusing on such changes.

5.3 The DiasNet interface and signs of adoption and empowerment: Copability

This interface analysis set out to clarify how DiasNet mediates the health behaviour of the nine patients in relation to the two issues of adoption and empowerment. The analysis was consisting of three elements.

A first element was to identify a number of use forms through open coding. The resulting four use forms were understood as four different concerns ('objects') of the patients when using DiasNet: to register their home monitoring data, to watch and reflect on them, to play with their data exploring various simulated adjustments, and finally to consult DiasNet as a decision support system to make adjustments in real life.

The second element was to code the material in terms of four levels of artefacts: from the first level, consisting of the actual system and related artefacts like mail and BG meters, through a system of three levels of higher artefacts, which the patients acquired, or developed themselves, as part of using the system.

Finally, the third element was to analyse the material to discuss the issues of adoption and empowerment, both by merely describing the identified categories, as well as by studying the distribution of the categories and their combinations statistically. This final element had two parts. The first part was focusing on use forms in terms of their distribution as well as their relation to coping types. The second part was focusing on artefacts. Here, the level of primary artefacts was given special attention, since the focus of the entire analysis was found on this level, the DiasNet system itself. Thus, the identified What artefacts were studied in relation to use forms as well as coping types. Concerning the higher-level artefacts, the discussion was based on the mere identification of the categories, as well as their distribution in the nine patient interviews (but not, however, in relation to either coping types or use forms). Concerning adoption, the mere existence of these higher-level artefacts was taken as indications of the amount of work the patients have done to integrate DiasNet into their health activity. Furthermore, concerning empowerment, the higher-level artefacts were discussed in relation to learning levels by providing in-depth discussions on examples of each sub-category.

To sum up on this interface analysis, I will look at the findings of each of issues of adoption and empowerment.

5.3.1 The adoption of DiasNet and related artefacts

Concerning the adoption of the DiasNet system itself, it is striking to see that, even though the Diabetes project was not unfolding as planned, leading to a lot of frustration in the patients due to a lack of feedback from the

clinicians, and even though surveillance seems to be essential, DiasNet still seems to have been widely adopted by the patients.

First, as an answer to the question of the toolness of DiasNet it seems to have been adopted by the patients in four ways in terms of the various use forms: Registration, reflection, exploration and intervention. While only registration was obligatory for the patients taking part in the Diabetes project the other use forms were not. Two of these use forms were dominating the use of DiasNet, being registration and reflection (see Fig. 5.4), the latter being even more common than registration. Thus, it seems that the patients in general to a large extent have made use of DiasNet in ways, which were not obligatory for them, especially for reflection. Concerning the mapping of use form codes with codes on coping types in the material, it was observed that each use form is related to many different coping types (see Fig. 5.4). This was taken as an indication that the patients employed the various use forms in many different ways. Again, a sign of adoption to a considerable extent of the DiasNet system.

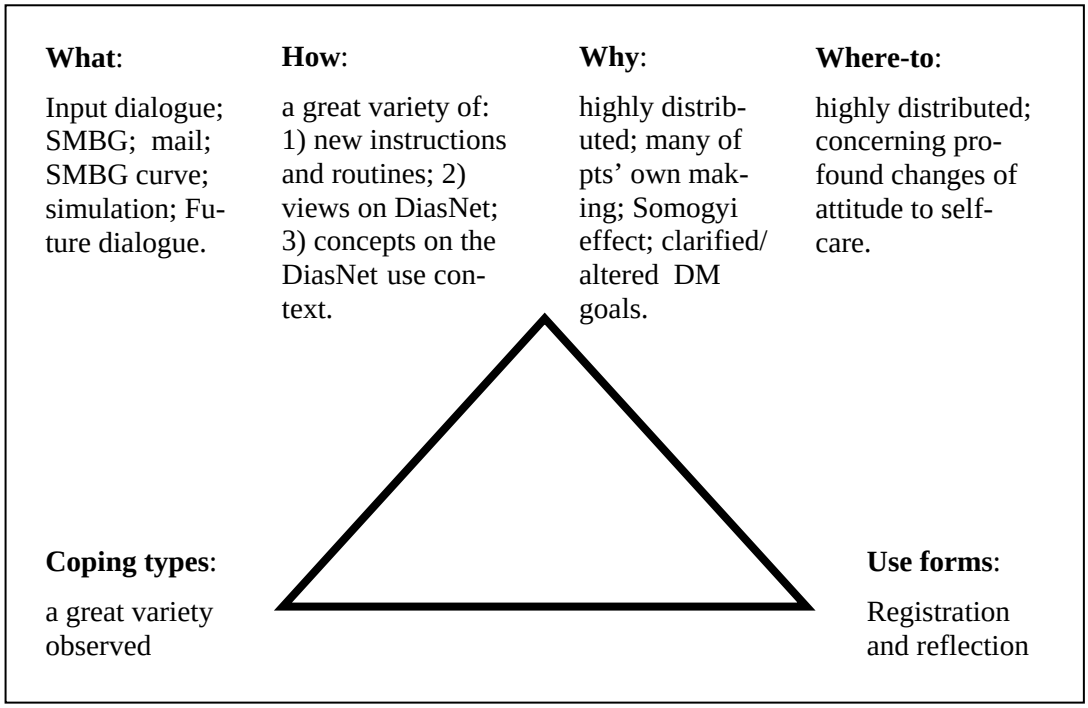

Fig. 5.4: Signs of adoption: Focusing on each of the three sets of categories, as well as in combination concerning primary artefacts, the interface analysis showed many signs of adoption – and own development of higher level artefacts – of the DiasNet interface among the nine patients.

Concerning the second part of the analysis, four levels of artefacts were identified as a way of describing the interface of DiasNet (see Fig. 5.4). Among the What artefacts, the Input dialogue, the use of SMBG, and

mail were adopted to a large extent for registration, being part of the obligatory use of DiasNet. In addition, the SMBG curve, the simulated BG curve, and the Future dialogue were widely adopted for reflection. And what is more, this was exceeding the obligatory use of DiasNet.

Among How artefacts, the analysis showed a great variety of 1) new instructions and routines, of which many were of the patients' own making; 2) views on DiasNet; 3) concepts on the DiasNet use context. That the patients had adopted these How artefacts in relation to the use of DiasNet was taken as a sign of considerable adoption of the system itself, as well as, of course, the How artefacts, of which the most widely distributed were related to the communication with the clinicians, SMBG routines, playing with own data, and using DiasNet as Mirror.

Concerning Why artefacts, these were highly distributed and several of the patients' own making, indicating adoption of the DiasNet system to a considerable degree. Furthermore, among the Why artefacts being mostly adopted were the hypothesis of the Somogyi effect, as well as clarified or altered disease management goals.

As for Where-to artefacts, their mere existence and their wide spread distribution (in all nine patients), as well as their make-up (visions about profound changes of attitude to self-care), were taken as clear indications of adoption of the DiasNet system. What is more, what also seems to have been widely adopted is the underlying agenda of the Diabetes Project to encourage self-care in terms of a more active, collaborative, and, ultimately, independent way of relating to diabetes and to the clinicians.

5.3.2 DiasNet and patient empowerment

The adoption of DiasNet and related artefacts also shows signs of supporting empowerment (see Fig. 5.5, next page).

Concerning use forms, the ones exceeding the obligatory use match with Roter's diabetes-related operationalisation of Freire's concepts on the three key consciousness raising experiences: relating and reflecting on experience, exploration and problem solving, and taking thoughtful action (cf. Chapter 1). Furthermore, the use form reflection having emerged from the patients' use, instantiating a patient-centric perspective. At the same time it appeared that all use forms were dominated by two coping types, which are topping the list of signs of empowerment concerning coping (cf. Chapter 4), i.e., routine-focused and problem-focused confrontive coping.

Concerning What artefacts, again, these were mostly related to the two focal coping types concerning empowerment (routine- and problem-focused confrontive coping). On the other hand, a few of the What arte-

facts (the Input dialogue, SMBG and the use of mail) were also to some extent related to emotion-focused distancive and problem-focused distancive coping, which are not taken as signs of empowerment.

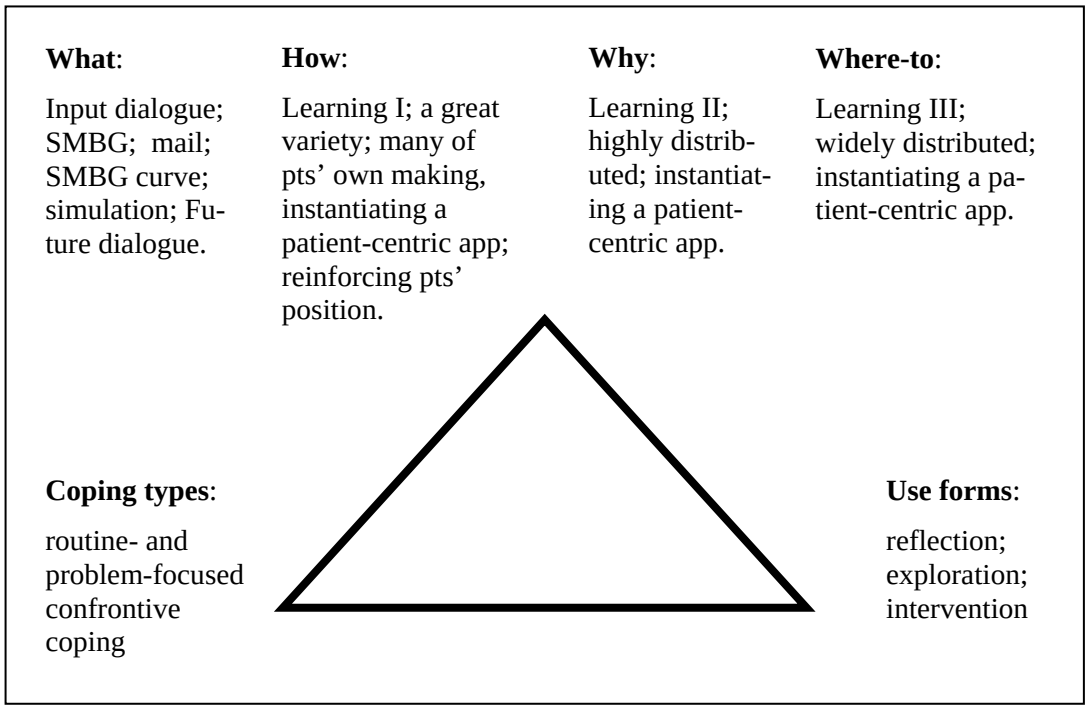

Fig. 5.5: Signs of empowerment: Focusing on each of the three sets of categories, as well as in combination concerning primary artefacts, the interface analysis also showed many signs of patient empowerment – and own development of higher level artefacts – of the DiasNet interface.

As for How artefacts, again, the long list of various sub-categories may illustrate that a considerable amount of Learning I has been taking place among the participants. Firstly, some of this learning had the form of following new instructions and taking up new routines (including 'action response'). Secondly, some of the How artefacts had to do with patient views on the use of DiasNet and related artefacts. Thirdly, some of the How artefacts had to do with understanding new concepts concerning the context of DiasNet use. Many of these How artefacts were of the patients' own making. In relation to this aspect, three participants expressed that they felt that using DiasNet had strengthened their position in discussions with the clinicians. If the concept of empowerment is connected to a patient-centric approach, this could be taken as a further indication that the patients' use of DiasNet has contributed to their empowerment. On the other hand, a variety of views were observed concerning the simulation facility of DiasNet, as well as how to relate to the communication with the clinicians. Such confusion was not considered a contribution to pa-

tients empowerment, while these How artefacts were still conceived of as instances of Learning I. Reflecting on this problem that Learning I does not necessarily imply patient empowerment it was argued that some concepts may be of a kind, which takes learning of a higher level than Learning I in order to be understood, or administered, correctly, e.g., a concept denoting a way of thinking, instead of merely denoting a routine.

The Why artefacts were identified as theory response – both concerning the Somogyi hypothesis, and many hypotheses of the patients' own making – as well as clarified and altered disease management goals. The patients' acquisition of these artefacts is seen as a sign of enhanced patient empowerment to a considerable extent: Firstly, in terms of their relation to the concept of Learning II, instantiating creative thinking of active and motivated patients; secondly their high distribution in the material; and thirdly, that they instantiate a patient-centric approach.

Finally, concerning where-to artefacts, all the patients discuss the use of DiasNet in a way that is coded as self manipulation for the purpose of focusing on self-care, e.g., to change a certain reluctance to take SMBG, or ways of altering the relationship to the clinicians. This way, the patients may deliberately employ DiasNet as a part of an environment to change a pattern of behaviour (a habit), or a pattern of contextualisation (an attitude). Hence, the Where-to artefacts are taken as strong indications that the use of DiasNet has contributed to patient empowerment among the nine patients, since: 1) they are representing a change of punctuation compared to the How artefacts related to the use of DiasNet; 2) such Learning III is widely distributed among the patients; and 3) it is instantiating a patient-centric approach *par excellence*.

6 Conclusion

6.1 Evaluating an ICT system's usefulness in supporting active patient participation in IDDM care

Since the results of the DCCT in 1993, there has been a call for employing ICT to support active patient-participation in IDDM care. One of the essential problems in developing and implementing a diabetes disease management system like DiasNet is its evaluation. Evaluation is defined as the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation) the result of which informs a decision to be made concerning that system in a specific context (Ammenwerth et al., 2004). Concerning the specific context of exploring the quality characteristics of DiasNet, it was implemented as part of the Diabetes Project at the Department of Internal Medicine at Vendsyssel Hospital in Frederikshavn, 2003-4. During this project 11 adult diabetes Type 1 patients were introduced to the system as a part of a diabetes school. The aim of the project was to gain experiences on the potentials of computerised diabetes care in general and DiasNet in particular, as well as its contribution to the self-care competences of the patients. My aim of this study is to present a way to evaluate DiasNet's potential contribution to meeting the challenges of patient participation in IDDM disease management. Thus, I will focus on its usefulness as a diabetes disease management system for patient use. In what follows, I will present the results of the study in terms of the development of a description method (copability), as well as the actual evaluation of DiasNet in accordance with this method (6.2). The outcome of the analysis in terms of its main conceptual elements (ideas), are listed in the following as bullet points marked with a 'ⓘ'. Finally, I will sum up on the contributions of this work to the field of studying evaluation methods for health informatics, and discuss some of the ways in which this contribution might be further developed (6.3). While the first section recapitulates on the process at length, the last two sections merely sum up on the results of the actual evaluation and the developed methodology in a more briefly manner.

6.1.1 A systematic literature review on ICT within IDDM care

ⓘ A systematic literature review was conducted on current literature on ICT systems research and development projects in IDDM care since the DCCT (from 1994 to 2004). Three basic approaches were identified, being doctor-oriented system, patient-oriented systems, and integrated doctor and patient-oriented systems. Among these three approaches, five categories of systems were identified: Data

management/ EMR (doctor-oriented systems); Decision support (primarily doctor-oriented systems); Computer assisted learning (primarily patient-oriented systems); Telemedicine (integrated doctor and patient-oriented systems); and Social support (patient-oriented systems). In spite of a call for systems supporting active patient-participation, the doctor-oriented approach seems to prevail in all five categories of systems. This trend also shows in a recent review listing 49 ICT systems in diabetes care, only a dozen of which are intended for patient use (Gorman et al., 2000).

ⓘ As a part of this review, I suggested a new way of categorising telemedicine and surveillance systems. Instead of focusing on differences in terms of various (and fast developing) forms of technology, I was inspired by an interactivity model presented by Jensen (1998) to categorise the systems in terms of the types of interactivity, which they were able to mediate. I accommodated Jensen's concepts to the present purposes, resulting in the following typology of telemedical interactivity: Transmissional, registrational, consultational, and supervisional interactivity. This part of the review showed, that, surprisingly, one of the most empowerment oriented systems mentioned were a low-technology transmissional system (based on 'non-directional telephone support'). Complementary to this type of telemedical interactivity, two supervisional systems (DIABTel and T-IDDM, both being highly comparable to DiasNet) are intended to support 'supervised autonomy' and 'patient independence', however, a) within limits set by the health professionals, b) while reserving decision support tools for the health professionals, and c) without monitoring patient participation and development in the feasibility studies.

6.1.2 Usefulness and the challenges of patient participation in IDDM care

ⓘ As a strategy for evaluating knowledge based systems (like DiasNet), Engelbrecht et al. differentiates between four levels of analysis: Verification, Validation, Human Factors Assessment, and Clinical Assessment (Engelbrecht et al., 1995), stating that Human Factors Assessment seeks to determine whether or not a system is useful and usable. However, concerning 'usefulness', I argue that an assessment of Human Factors Assessment is closely related to clinical assessment. While existing evaluations of DiasNet and earlier versions of this prototype have mainly focused on its use as a medico-centric decision support system in order to find ways of refining the model, I decided to focus on DiasNet's potential contribution to meeting the challenges of patient participation in IDDM

disease management. In doing this I claim that the traditional focus on the medical benefits in terms of metabolic parameters needs to be complemented by other criteria of quality of care, which are relevant in the given context of patient-participation in diabetes disease management. Within this debate, 'patient empowerment' was found a frequently used term. By reference mainly to Freire, this concept was discussed as being founded on an emancipation discourse as opposed to the traditional medico-centred 'compliance approach' to patient education. Whereas the latter may reinforce powerlessness and helplessness, reducing patient autonomy and constraining freedom of choice, in contrast the empowerment approach is focused on helping patients in developing self-awareness about their own health values, needs, and goals to become equal and autonomous members of their healthcare team. However, the proper use of the empowerment concept and its influence on the actual delivery of health care services was described as a controversial and highly complex matter. What seems to be a safe conclusion is that 'empowerment' can be understood as an approach, which conceives of the individual patient as more than merely an 'object' of health care, and which emphasises collaboration between patients and health professionals in a way that deviates from a traditional focus on compliance and adherence. Also, the concept thus seems to be connected to a concept of patient learning, which entails many more aspects than merely acquiring basic disease management skills.

6.1.3 Studying usefulness: the approach of the CID project

ⓘ The ultimate goal of this project was to find a way to evaluate the DiasNet system's potential in enhancing the users' ability 'to cope' – not with the system itself, as when focusing on user acceptance in a more narrow sense, but with the users' challenges, tasks, or interests. 'Copability' was coined as a term for this change of focus, as opposed to merely studying utility, or traditional usability ('user-friendliness') aspects. I therefore decided to follow the Diabetes Project in order to develop this concept within a concrete context of implementing a piece of ICT equipment (DiasNet) to support disease management among diabetes patients. More concretely, in the description of the usefulness of DiasNet I wanted to describe two main issues. Firstly, the degree to which it was adopted by the patients as a part of their health behaviour. Secondly, I also wanted to describe the benefits of this adoption, as well as the resulting changes of their health behaviour, in terms of 'patient empowerment'. This second issue was due to the influence

of this concept on the current debate on active patient participation within diabetes care in general, as well as the more specific goal of the Diabetes Project.

ⓘ To study these issues, the main question was how to study their common issue of artefact mediation. As a theoretical approach to this question I chose the school of CHAT. My motivation for choosing the CHAT approach as the theoretical stance on studying the usefulness of DiasNet was two-fold. First, it seemed suitable for studying both the integration of mediating artefacts (the adoption theme) as well as the development of human activity (the empowerment theme). Second, much interest is currently drawn to CHAT within the field of Human-Computer Interaction (Bødker, 1987; Engeström, 1996; Nardi, 1996; Collins et al., 2002; Korpela et al., 2002; Mwanza, 2002). The school of CHAT can be conceived of as a large and varied tool box of generic principles for analysing specific contexts, in this case the mediation of proficient self-care. My approach to employing these analytical tools was not to use any one of them directly, but to get inspiration from them in developing my own analytical concepts through an explorative and qualitative study, and to understand their relations in terms of a general conceptual framework. In choosing this theoretical stance, the CID project was thus mainly oriented toward the research field of Human-Computer Interaction, apart from Health Informatics.

ⓘ As a method for the more identification of the more specific analytical concepts I was inspired by grounded theory. A detailed account of the developmental process of this explorative and qualitative study and its contextual conditions was given in Chapter 2.

6.1.4 Artefact mediation: Artefact types, activity aspects, and learning levels

Inspired by Engeström (1987) and his conflation of three conceptual hierarchies, I have provided a critical discussion of Bateson's learning levels, Leontiev's activity aspects, and Engeström's artefact levels (derived from Wartofsky), leading to the presentation of an altered relation between these conceptual hierarchies, as well as to the combination of these concepts with a fourth set of categories concerning action forms (inspired by Wartofsky).

ⓘ To summarize on my interpretation of Bateson's learning theory, it emphasizes two important aspects. Firstly, it is understood as a way of describing learning levels in terms of logical types of changes of information processing. This basic principle of description is illustrated by the experiment with the dolphin. In my read-

ing of this experiment, the qualitative change in the dolphin's way of learning to display new pieces of behaviour was understood as a shift from Learning I to Learning II. Simply learning to display a certain piece of behaviour is Learning I. But learning to change behaviour at each performance is learning of a higher logical type. Furthermore, this shift was understood in terms of a change in punctuation of context. And this explanatory principle is understood as the second important aspect of Bateson's learning theory. With respect to this second principle, I emphasized Bateson's observation that there is a necessary relation between the notion of context and learning at higher levels than Learning 0.

ⓘ To summarize on my discussion of Engeström, it set out from his 1987 conflation of three conceptual hierarchies, being concepts of activity, artefacts and learning. I argued that it was reasonable to believe that this conflation also applies to his expanded classifications about learning and artefacts, which he presented in 1987 and 1990, respectively. I thus claim that in Engeström's thinking, Learning I, IIa, IIb, and III correspond to What, How, Why, and Where-to artefacts, respectively. Also, that the top and bottom level of these hierarchies are supposed to be corresponding to 'operation' and 'activity' in terms of activity levels, whereas the pair of middle level concepts correspond to 'action'. I value the intent of Engeström's overall idea to integrate the concepts on learning and artefacts, as opposed to Bateson who does not provide much help in analysing artefacts in learning processes. Also, I find his expansion of Wartofsky's concepts useful. Thus, I accept his alternative classification in his description of What, How, Why, and Where-to artefacts. However, I do not agree on the way Engeström relates his artefact classification to Bateson's learning levels. First of all, Engeström seems to forget about Learning 0. However, as I argue, processes at this learning level are mediated by primary What artefacts. Secondly, I do not agree that it is possible to distinguish between Learning IIa and IIb as suggested by Engeström. Thirdly, in my view How and Why artefacts correspond to Learning I and II, respectively. Finally, I would like to point out that Learning III does not 'correspond' to the use of Where-to artefacts, since their use does not necessarily lead to Learning III, and thus Learning III cannot be identified with the employment of Where-to artefacts. I agree with Engeström that Where-to artefacts may mediate Learning III processes, i.e., in deliberate reflections leading to Learning III. But, as Engeström points out himself, such processes take up a lot of time and effort. As a part of this discussion, I

emphasise the possibility of an individual Learning III processes. Hence, contrary to Engeström I am prepared to use the label of Where-to artefacts on individual use of artefacts mediating Learning III processes, by referring to his own example of the developmental process of 'Huckleberry Finn'.

- In my discussion, I took a phenomenological approach to concepts within CHAT. First, by stressing the point that active human beings always are in action when taking care of their daily business (cf. the discussion of Heidegger's concept of *Sorge* above), however, not always focusing on primary actions. Next, by drawing on Heidegger's concept of breakdown, suggesting that learning levels apply to various levels of reflection (initiated by breakdowns in primary actions) on various activity aspects. Consequently, when Engeström claims that secondary artefacts correspond to the 'action level', I conclude that this should not be understood in the primary sense of being in action. Instead, I suggested that a subject may relate to his or her activity at various levels of abstraction, i.e., at various levels of reflection on a primary action, in other words, various ways of 'being in action' while focusing on a certain aspect of one's activity. Also, inspired by Wartofsky, I suggested the existence of four forms of action each corresponding to one of the four levels of reflection.
- Furthermore, I suggest that the levels of reflection can be described in terms of a change of punctuation, i.e., in terms of learning levels. In this way, Learning 0 corresponds to an initial situation of a primary unreflective form of action in which the subject is merely taking account of the relevant information in the environment. As for learning level I through III, these correspond to three ways of reflecting on this primary form of action. For example, in Learning I, there is a change in punctuation when the subject leaps from merely noticing the actual conditions to becoming aware of the context it is facing, and then learning what must be done in such a context, much as when a dog is trained to display a certain behaviour at a given signal. Whereas Learning I entails a reflection on the initial Learning 0 situation, Learning II entails a reflection on Learning I situations, as Learning III can be reached by way of a reflection on outcomes of Learning II.
- Finally, I suggest that certain types of artefacts mediate each levels of reflection, i.e., that What artefacts mediate un-reflective primary actions, whereas How artefacts mediate secondary actions reflecting on means and conditions, and so forth.

ⓘ As a part of this discussion, I criticised a common notion within CHAT of 'machine-like operations' pointing out that primary actions and operations are not the same. Also, Learning 0 does not correspond only to the 'operation level' in terms of relating to the conditions in the environment. All three activity aspects are necessary to describe this form of action, since the subject is also relating to the object in terms of a certain goal, or certain goals, guiding the activity, and in terms of a motive that is initiating the activity and giving it momentum as an answer to a need. The discussion on the concept of primary actions may seem quite academic. Nevertheless, it addresses an important issue concerning approaches to self-care activities, namely the difference between thinking of self-care actions in terms of 'dull routine', or – more engagingly – in terms of 'playing', or 'surfing'. I want to stress that primary behaviour does not have to be dull behaviour following a strict pattern of actions being carried out in a mind-less and inflexible manner. Primary actions can also be carried out in a more flexible way, such as an expert performance at Learning level 0. Hence, in my phenomenologically inspired approach to CHAT I have sought to interpret the concept of primary actions as wide enough to include both attitudes to everyday routines.

6.1.5 Artefact mediation: Health actions, coping, and empowerment

ⓘ The concept of coping is employed to provide a systematic description of the most relevant aspects of the patients' behaviour and thoughts, i.e., their health actions. In this study, coping means *a diabetes patient's own internal or external actions in order to manage an appraised problem concerning disease management*. This coping definition is mainly inspired by the Lazarus-Folkman approach. The two 'classical' coping functions identified by Lazarus/ Folkman are called 'problem-focused coping' and 'emotion-focused coping', being focused either on changing the realities of a stressful situation, or the emotional response to it, respectively. The core of the Lazarus-Folkman approach to coping is the concept of appraisal and the construction of relational meaning as a situation specific process. Whereas the Lazarus-Folkman approach originally was tied to a 'process approach' as opposed to a 'structure approach', Lazarus later advocated a third approach which is open to taking account of certain personal traits influencing the process of appraising. Importantly, I argue that Lazarus' correction of the process approach makes it possible to include disease management routines as part of coping if such routines are employed as

the result of an appraising of situation specific conditions which are made 'functionally equivalent' with relation to a certain goal commitment.

A number of similarities were pointed out between CHAT and the Lazarus-Folkman approach to coping, the most important being the concept of cognitive mediation, and the concept of a subject's 'relational meaning' as a transactional process, as well as the prominence of studying concrete contexts. Also, Lazarus' (1999) way of describing the onset of stress is close to describing breakdown situations, since both concepts are described in terms of environmental conditions obstructing the attainment of a goal commitment. Finally, Lazarus' 'third approach' of studying traits in terms of 'functionally equivalent conditions' seems to be in harmony with analysing how a person is orienting himself in terms of a 'motive'. I therefore suggest integrating the two approaches by viewing coping processes as an integrated part of human activity. Whereas coping theory provides a detailed analysis of how a stress response unfolds in a breakdown situation, the CHAT approach may provide a deeper analysis of the background of what comes before such breakdown situations in terms of 'unhampered' daily activity. In addition, while the concept of artefacts seems to be missing in the list of personality and environmental variables influencing the process of appraisal as discussed by Lazarus (1999), the CHAT approach may supplement the coping analysis with the concept of mediating artefacts.

ⓘ A number or examples on how coping analysis applies to diabetes was discussed from the literature. None of the studies included in this review (Lundman, 1990; Bott *et al.*, 1997; Nomura *et al.*, 2000; Karlsen & Bru, 2002; Seiffge-Krenke *et al.*, 2003) seem to be in alignment with the transactional Lazarus-Folkman approach (Lazarus & Folkman, 1984). Instead, all of the studies were focusing on coping styles (a 'structure approach'). Nevertheless, all of the studies were heavily influenced by the Lazarus-Folkman approach in other ways. Thus, most of the coping strategies were categorised in terms of a fundamental distinction between external, active, problem-focused, and task-oriented coping on the one hand, and internal, passive, emotion-focused, and distancing coping on the other hand. A number of coping strategies, however, proved difficult to categorise this way, including '*seeking social support*' and '*routinization*' (both active and passive).

ⓘ Using open coding procedures I avoided applying coping concepts from the literature. Instead, I labelled a given passage by a short

description being delimited by the small number of characters that NVIVO 2.0 allows for labelling. The resulting small chunks of labelled text each representing a specific piece of coping behaviour then became my 'data' in terms of specific 'coping strategies' being employed by the patients in various occasions of coping. These coping strategies were categorised as ten different types of coping, which I defined as the combination of two coping functions and five coping forms.

Firstly, I felt that it was meaningful to operate with a dichotomy concerning coping functions. Yet, I avoided employing the concepts of emotion-focused and problem-focused coping to do so. Instead, the key distinction I focused on was to be either 'confrontive' or 'distancive' when a patient is facing disease management problems. Since diabetes is a controllable disease in which patient self-care is of paramount significance, I found this distinction to be most relevant. I therefore decided on this difference to be my primary concern when categorising the coping strategies. To further specify in terms of which problem the primary relational difference should be identified, I decided on metabolic control, since this issue is the *raison d'être* of DiasNet. Unlike the Lazarus-Folkman approach, I use this distinction as a dichotomy to distinguish between different coping strategies (as analytical concepts), while many coping strategies can be employed in a single process of coping, thus representing both confrontive and distancive coping functions. In deciding on this primary conceptual distinction, I may be criticised for choosing a medico-centric perspective. However, my definition of the most relevant relational difference in this study does not reflect a judgment on my part concerning what is the most important issue that a patient ought to focus on in dealing with diabetes. Instead, my choice of perspective is motivated in two ways, which differs from merely taking a medico-centric approach. Firstly, my primary concern is to study DiasNet as a learning artefact. As a tool DiasNet was primarily built to support doctors in dealing with the problems of metabolic control in their patients. When being presented to the patients as a learning tool, then, DiasNet carries this agenda with it. Hence, as a descriptive method, I find it most relevant to study to what extent the patients actions are in alignment with this agenda when studying DiasNet as a learning tool. Secondly, the relational difference is not defined as an instrument to distinguish between 'good' and 'bad' coping.

Secondly, to further describe a given coping strategy in terms of its 'coping form', i.e., the way in which a certain coping function

shows. I suggest that the traditional pair of concepts concerning coping functions (and can be regarded as different 'forms' of coping. In addition to these coping forms I will employ a number of other concepts found in the literature which I found particularly relevant in my analysis: Acute internal (emotion-focused) coping, acute external (problem-focused) coping, long-term internal coping (meaning-focused), and long-term external (routine-focused) coping, as well as contact-focused coping. Each of the five coping forms was found in the two groups of confronting and distancing coping strategies, resulting in ten different 'types' of coping strategies.

- Furthermore, I suggested interpreting findings on coping in terms of patient empowerment. From a medico-centric perspective I suggest that the confrontive coping function has a higher rank concerning empowerment than distancive function. Furthermore, as for coping forms I suggested the following rank: routine-focused coping, problem-focused, meaning-focused, and emotion-focused coping. Contact-focused confrontive coping is not a part of this list, but may function as a vehicle for all of them.

- Finally, taking the identified coping strategies (strings of text) in the nine patient interviews as the foundation for the study of DiasNet's integration into the patients' health actions, a second coding phase was looking into these text passages in order to identify instances of artefact use. Some of these artefact mediated health actions were directly or indirectly related to the use of DiasNet, while some were not. In what follows, the first group will be labelled instances of computerized diabetes disease management (CDDM). Looking into coping in the nine patients in relation to the introduction of DiasNet, it appeared that a large portion (40%) of the coping strategies discussed by the patients a year after the onset of the Diabetes project is related to DiasNet. Hence, concerning the adoption theme, this indicates that the group of patients have adopted DiasNet as an integrated part of their health behaviour to a fairly large extent. Furthermore, the analysis provided some indications of how DiasNet has been adopted in terms of the character of the coping being related to it. Firstly, concerning the basic distinction between confrontive and distancive coping the analysis indicates that there is a closer connection between CDDM and confrontive coping than distancive coping. Next, concerning which coping types were most commonly being related to DiasNet it was found that in three confrontive coping types more than half of the passages are related to CDDM, namely routine-focused,

problem-focused, and emotion-focused confrontive coping. Hence, it seems that the way DiasNet primarily has been adopted into the patients health behaviour is to support long-term preventive behaviour, acute problem solving, as well as in keeping up a good spirit. It seems that DiasNet has contributed to patient empowerment. Firstly, CDDM seems to have a closer relation to confrontive coping than to distancive coping. Secondly, the two coping types which seem to have the closest relation to CDDM, routine-focused and problem-focused confrontive coping, are topping the ranking system of coping types contributing to empowerment. In addition, emotion-focused confrontive coping, which is also contributing to patient empowerment, also to a considerable degree seems to be related to CDDM. At the other hand, there also seems to be some relation between CDDM and emotion-focused distancive coping, which is not contributing to patient empowerment from a medicocentric point of view. This raises the question whether these findings indicate that DiasNet promote confrontive coping instead of distancive coping, or that confrontive coping is more open to the adoption of new artefacts like DiasNet. Since this study only to a slight degree is open for a comparison of the patient's coping at the beginning of the Diabetes project and a year after, it does not provide an answer this question.

6.1.6 Artefact mediation: Use forms, and artefact types

ⓘ While focusing on health actions, a coping analysis does not in itself provide much insight into how DiasNet is integrated as an artefact into the patients' health actions, i.e., how it is used as a tool. Concerning 'toolness' an artefact can mediate many different purposes, and, in effect, have many different appearances as a tool. My term for this is use forms. The use forms can be conceived of as the various ways in which the tool is a mediating interface between a subject and his or her 'object'. Hence, one element of the DiasNet interface analysis was to identify the various concerns of the nine patients when using DiasNet. The resulting four use forms were: Registration, reflection, exploration and intervention. Concerning the toolness of DiasNet it thus seems to have been adopted by the patients to register home monitoring data, to watch and reflect on them, to play with the data exploring various simulated adjustments, and finally to consult DiasNet as a decision support system to make adjustments in real life. Three of these use forms did not come as a complete surprise. While interviewing the patients I had asked them about the merits of DiasNet as a system for reporting data to the clinicians, a decision support system, and as a learn-

ing tool. The first two were mapping the use forms Registration and Intervention, while the latter was conceived of as an aspect of the use form Exploration. However, when coding the material a fourth type of concern appeared to be widely distributed among the patients: to merely keeping in check of the patterns of their own data as visualised in DiasNet – as if they were often using DiasNet as a 'mirror' to keep in check of their current metabolic state of affairs.

ⓘ Still, the concept of use forms was not primarily designating the actual artefact, but only the various ways of using this artefact. The word 'screwdriver' can be understood as both a noun (a concrete artefact) and a verb (a certain proper form of action in which the artefact is employed, instead of using the physical item as, e.g., a hammer). Likewise, the use forms can be considered as various proper forms of actions, or 'verbs', when employing DiasNet. Hence, the 'nouns' were still missing in the analysis to describe the multifaceted toolness of DiasNet in a more detailed manner than merely referring to the system as a whole. Also, I wanted to study the use of these artefacts not only in terms of primary artefacts (physical What artefacts), but also in terms of How, Why, and Where-to artefacts. Hence, a second element of the interface analysis was to code the material in terms of four levels of artefacts: from the first level, consisting of the actual system and related artefacts like mail and BG meters, through the three levels of higher artefacts – such as instructions, theoretical explanations, and visions of the future – which the patients acquired, or developed themselves, as part of using the system. The most common of these artefact types are mentioned below.

6.1.7 Interface analysis and copability

ⓘ The main conceptual idea and overall aim of this study was to describe the 'copability' of DiasNet, i.e., its usefulness in supporting self-care of the nine diabetes patients. Hence, I wanted to describe to which degree it was adopted to mediate their (own) health actions. And due to the influential concept of patient empowerment in the debate about active patient participation as well as on the description on the goal of the Diabetes Project, I also wanted to describe DiasNet's benefits in terms of this issue. To analyse these issues I have described three sets of concepts: Coping types, use forms, and artefact types. Again, the first set of concepts are describing the relevant health actions in which DiasNet is used, while the two other sets are used for describing the interface of DiasNet (its 'toolness') in terms of typical concerns for using the system

(use forms), and the actual physically present artefacts when using it (What artefacts), as well as the more mentally represented artefacts being employed as a part of using DiasNet (How, Why, and Where-to artefacts). The diagram (Fig. 6.1) illustrates the relationship between the resulting three sets of concepts describing the various levels of artefacts (artefact types) mediating a subject's health behaviour (coping types) when having various focal concerns (use forms). Together, these three sets of concepts form an 'interface analysis' of DiasNet. Next, in terms of carrying out an evaluation relating to a specific decision-making context, this descriptive 'interface analysis' is then used normatively by relating it to specific goals of implementing DiasNet, as a 'copability analysis'. Hence, the copability analysis further studies the usefulness of DiasNet in terms of how it is integrated into dealing with diabetes as a part of the patients' everyday lives, both in terms of 'adoption' and 'patient empowerment'. These two issues of the copability analysis, adoption and empowerment, can be analysed when focusing on each of the three sets of concepts of the interface analysis, as well as – ultimately – when using them in combination. More on this in what follows.

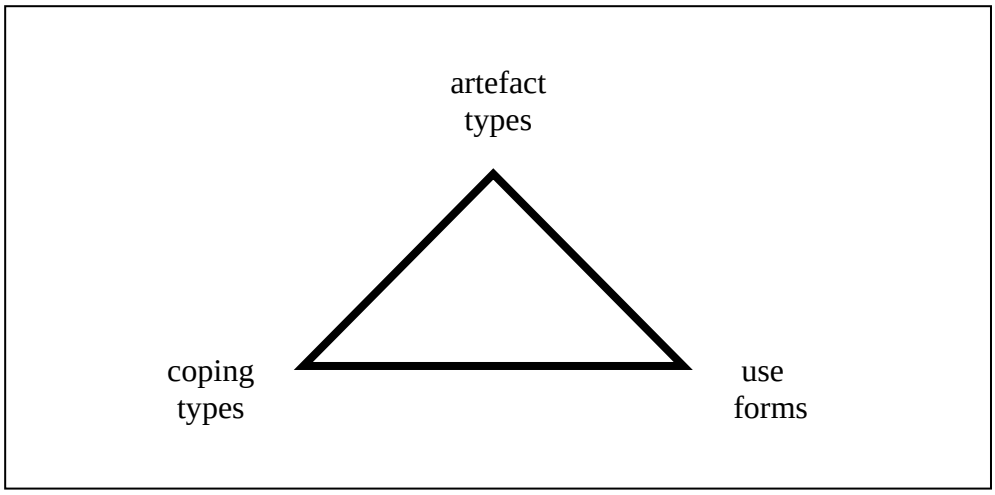

Fig. 6.1: The interface analysis in terms of coping types, use forms, and artefact types.

6.2 DiasNet and copability: Adoption, and empowerment

Having described the three sets of concepts, the final task was to analyse the nine patient interviews to discuss the issues of adoption and empowerment, both by merely coding the material in accordance with the identified categories in order to discuss examples, as well as by studying the

distribution of the categories and their combinations statistically. This analysis had two parts.

The first part was focusing on use forms in terms of their distribution as well as their relation to coping types:

- Concerning adoption of use forms, only registration was obligatory for the patients taking part in the Diabetes project. Hence, the mere emergence of the three other use forms was taken as indication of adoption to a considerable extent. Furthermore, each use form appeared to be related to many different coping types, indicating that the various approaches to DiasNet appeared in many different health actions.
- Concerning use forms and empowerment, it appeared that all use forms were dominated by two coping types, which are topping the list of signs of empowerment concerning coping (cf. Chapter 4), i.e., routine-focused and problem-focused confrontive coping. What is more, a clear match was noticed between the use forms exceeding the obligatory use and Roter's diabetes-related operationalisation of Freire's concepts on the three key consciousness raising experiences: relating and reflecting on experience, exploration and problem solving, and taking thoughtful action. In addition, the use form reflection having emerged from the patients' use can be said to instantiate a patient-centric perspective in particular.

The second part of the analysis was focusing on artefacts. Here, the level of primary artefacts was given special attention, since the focus of the entire analysis was found on this level, the DiasNet system itself:

- Thus, the identified What artefacts were studied in relation to use forms as well as coping types. It appeared that the Input dialogue, the use of SMBG, and mail were adopted to a large extent for registration, being part of the obligatory use of DiasNet. In addition, the SMBG curve, the simulated BG curve, and the Future dialogue were widely adopted for reflection, thus exceeding the obligatory use of DiasNet. Concerning empowerment, the What artefacts were mostly related to the two focal coping types concerning empowerment (routine- and problem-focused confrontive coping). On the other hand, a few of the What artefacts (the Input dialogue, SMBG and the use of mail) were also to some extent related to emotion-focused distancive and problem-focused distancive coping, which are not taken as signs of empowerment.
- Concerning the higher-level artefacts, the discussion of adoption was based on the mere identification of the categories, as well as their distribution in the nine patient interviews (but not, however,

in relation to either coping types or use forms). The mere existence of these higher-level artefacts as well as their distribution were taken as indications of the amount of work the patients have done to integrate DiasNet into their health activity. What is more, what also seems to have been widely adopted is the underlying agenda of the Diabetes Project to encourage self-care. Furthermore, concerning empowerment in relation to the higher-level artefacts, in-depth discussions on examples of each sub-category were provided in relation to learning levels. As for How artefacts, new instructions and taking up new routines were discussed as indications of enhanced empowerment. As a part of the analysis of these examples, it turned out to be a problem that not all instances of Learning I were taken as indications of patient empowerment. Reflecting on this problem it was argued that some concepts may be of a kind, which takes learning of a higher level than Learning I in order to be understood, or administered, correctly, e.g., concepts denoting ways of thinking, instead of merely denoting more concrete phenomena. Concerning Why artefacts, the Somogyi hypothesis, and the many hypotheses of the patients' own making, as well as the many examples of clarified and altered disease management goals were taken as indications of creative thinking of active and motivated patients. In addition, their high distribution in the material as well as their instantiations of a patient-centric approach were taken as indications of empowerment. Concerning Where-to artefacts, the examples of self-manipulation for the purpose of focusing on self-care (e.g., to change a certain reluctance to take SMBG, or ways of altering the relationship to the clinicians) instantiate a patient-centric approach *par excellence*, since they mediate Learning III. Also, this artefact level was found to be widely distributed among the patients. However, in itself this was not taken as an indication that Learning III was taken place to this extent.

6.3 Perspectives for further research

To finally sum up on the contributions of this work I will use a terminology recently described by Jytte Brender concerning evaluation methods for health informatics (cf. Brender, 2006). In short, then, what has been presented is 1) a 'methodology' for the 'constructive assessment' of a patient-oriented disease management system, as well as 2) an 'evaluation' of DiasNet according to this methodology. In what follows, I will concentrate on the first part to expand on the ways in which this methodology may contribute to the research field of evaluation methods within health informatics. Thereafter, I will comment on the future perspectives of em-

ploying and advancing the current contribution with reference to Brender's collection of state of the art evaluation methods (cf. Brender, 2006).

6.3.1 Copability analysis as an ICT assessment methodology

In terms of ICT assessment (cf. Brender, 2006), the intended use of the copability analysis primarily is to support decision making in implementation and ongoing re-design of a system, i.e., **constructive assessment**. Also, in terms of **evaluation**, which requires a certain decision-making context, it concerns the adoption of a certain system, DiasNet, being implemented with the aim to support patient empowerment in diabetes (type 1) outpatients.

In terms of 'The Metrology Framework' (cf. Brender, 2006), I will describe the copability analysis as a **methodology** mediating, on the one hand, a conceptual **framework**, and on the other hand, a number of **methods**. As for the conceptual framework, the integration of mediating artefacts has been described in terms of the triangular model comprising the subject, the mediating artefact, and the object. The methodology founded on this conceptual framework comprises: 1) a number of methods each relating to a node in this triangle, as well as 2) a procedure for their use. As for the first element, the methods consist of a) a **coping** analysis, b) an **artefact** analysis, and c) a **use form** analysis – in combination being understood as an **interface** analysis of DiasNet. As an evaluation, this descriptive interface analysis is then used **normatively** by relating it to the specific goals of implementing DiasNet: as a **copability** analysis, describing the usefulness of DiasNet in terms of adoption and patient empowerment.

To recapitulate on the copability analysis, I will describe the two elements of the methodology (its methods and the procedure for employing them) in more detail below.

Concerning the first element (the methods), beginning with the 'subject' node, the copability analysis of DiasNet began with a coping analysis, which characterised the subject's attitude and way of acting in terms of coping. This analysis identified a number of **coping strategies**, which are understood as the relevant situations to study, i.e. as **health actions**, of which some are mediated by DiasNet and related artefacts, i.e., computerised disease management (**CDDM**). Next, it characterised these health actions in terms of two **coping functions** as either **confrontive** or **distancive** coping in relation the **focal relational difference**, being identified as to obtain metabolic stabilisation, which is the *raison d'etre* of DiasNet. And finally, it characterised instances of either coping function in terms of five **coping forms**, thus operating with 10 **coping types**.

Building on the identification of CDDM, the copability analysis included an analysis of the 'object' node in terms of various **use forms**. Through open coding a number of interests, or purposes was identified as **registration**, **reflection**, **exploration**, and **intervention**.

Concerning the last node in the triangle an artefact analysis was carried out. Artefacts of four artefact levels were identified as **What**, **How**, **Why**, and **Where-to** artefacts, and within each artefact level a number of subcategories were identified.

As for the second element (the procedure), the identifications according to each method were understood as **metrics** of the copability analysis to discuss to the two questions of **adoption** and **patient empowerment** – the latter being the **aim of the Diabetes Project**. To supplement this discussion based on the mere identification of the phenomena, the number of the individual occurrence of each of the metrics as well as (some of) their combinations were **counted** by way of queries.

Concerning adoption, this theme was discussed in relation to: 1) a comparison of CDDM and non-CDDM; 2) the mere existence of non-obligatory use forms; and 3) the variety of higher-level artefacts as well as their relation a great number of coping types.

As for patient empowerment, this discussion was somewhat more complicated: Concerning coping types, a ranking of the 10 coping types was suggested regarding their likelihood of contributing to obtaining metabolic control (the focal relational difference), thus entailing a **medico-centric perspective**. Regarding use forms, the non-obligatory use forms each had a parallel to a stratification of concepts concerning patient empowerment, while also the mere identification of these use forms was seen as complementing the medico-centric coping analysis with a **patient-centric perspective**. And finally, the analysis regarding artefacts was the most complicated. Concerning the primary artefacts, their occurrence were analysed in relation to both **coping types** and **use forms** as ways to study their contribution to patient empowerment, while the mere identification of the higher-level artefacts was discussed in terms of their mediation of **higher-level learning**.

6.3.2 Further research to advance the current contribution

Being described this way, in terms of its underlying conceptual framework as well as its procedure, the copability analysis could be considered a more generic methodology, which – in its current form – is devised for use in a particular context, but which might be transferable to other context of employing ICT in health care and many other context as well. Here, it could be discussed how the copability approach relates to existing

evaluation methods. Comparing it to the collection of methods recently being described by Brender, it perhaps most likely integrates with the 'equity implementation model' for use in the adaptation phase of a system's development, or alternatively the 'impact assessment' for use in the evolution phase. The first method is described as an assessment method to:

> 'retrospectively investigate and understand user reactions to the implementation of an IT-based system, based on incidents in an organization. The focus of this method that originates in social science is the effect of the changes that such a system brings about' (Brender, 2006, p.109).

The impact assessment is described the following way:

> Measurements of the effect – that is, the consequences or impact in its broadest sense from degree of realization of the objectives plus assessment of side effect – of an IT-based solution, with or without the original objective as a frame of reference. Hence, it includes not only the beneficial effects, but also potential adverse effects.' (Brender, 2006, p.135)

Concentrating on its current context, the intended use of the evaluation methodology primarily is to support further development of DiasNet system as well as the use of it to support active patient participation in diabetes care, in short – to support the development of CDDM. Used in this way, the analysis can be used as a basis for deciding on which aspects of DiasNet to improve in further developing its interface. This could be done by merely taking account of the patients' adoption (and some times own development of the What artefacts. Furthermore, this process could integrate How artefacts in order to better support certain routines, but it is not clear how the two top-level types of artefacts could support such enterprise. However, the other aspects of the interface analysis, the use forms, could be employed, e.g., in analysing how to re-arrange the facilities of DiasNet – or perhaps even to split up the facilities on a number of different devices. Also, this redesign process could focus on certain aspects of the DiasNet interface, which appeared to be particularly related to empowerment.

As a second way of employing the copability analysis, it could support the implementation of DiasNet or a similar system. When implementing the system, the clinicians could consider a number of various questions, like: Which ways of using the DiasNet system would we like to stimulate to enhance adoption and patient empowerment? (Concerning the latter issue, it is noteworthy that the three use forms exceeding the obligatory use in the Diabetes Project were particularly related to empowerment.) In turn, which ways of using DiasNet would we like to warn against (such

as, the routine-focused distancive health action of ‘passing on the monkey to the clinicians’ as a part of registration)? Again, observations on both parts of the interface analysis, the use forms and the four levels of artefacts could help to support the implementation and adoption of DiasNet to enhance empowerment. Since the patients develop much of the interface aspects, such enterprise may be considered an example of participatory design. Also, during an implementation process the concepts could help in monitoring the developments in terms of adoption and empowerment of the patients.

To provide a firm basis of such enterprises of re-designing DiasNet and the way of implementing it in diabetes care, the copability analysis could be re-considered concerning patient empowerment. In more general terms, it could be questioned: What is the relation between quality of care and certain coping types, use forms, and artefact types? Such questions may be difficult to answer without asking the patients themselves, and their clinicians. In very concrete terms, such a debate could perhaps be taken as a part of a diabetes school setting, or the issue could be further explored in more general terms by way of workshops of interviews with groups of representative users to support further development of CDDM.

7 Literature

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8 Summaries

8.1 Summary

Copability in Disease Management (CID) is a PhD project (2002-5) as part of the monitoring research in connection to The Digital North Denmark (Det Digitale Nordjylland, DDN, 2000-3), monitoring the Diabetes Project (2003-4) at Vendsyssel Hospital where 11 adult outpatients were introduced to a computer-based disease management system for diabetes patients (DiasNet). One of the essential problems in developing and implementing a system like DiasNet is its evaluation. The CID project thus focuses on evaluating DiasNet's usefulness in meeting the challenges of active patient participation in IDDM care. However, very little literature is found on how to evaluate computer-based disease management systems for chronically ill patients. The project, therefore, is an explorative and qualitative study, which 1) develops an evaluation methodology (the copability approach) describing the integration of disease management systems into patients' health actions, while evaluating this in terms of adoption and empowerment, and 2) provides an evaluation of DiasNet, accordingly.

Since the results of the DCCT in 1993, there has been considerable research in ways of employing ICT to support intensive insulin therapy in IDDM care. A systematic literature review was conducted on current literature on ICT systems research and development projects in IDDM care since the DCCT (from 1994 to 2004). It shows that, in spite of a call for systems supporting active patient-participation, the doctor-oriented approach seems to prevail. Also, among telemedicine and surveillance systems, it shows that, surprisingly, a low-technology transmissional system was found to be contributing to empowerment to a larger extent than even two much more advanced supervisional systems similar to DiasNet, being devised to support 'supervised autonomy' and 'patient independence'. Compared to such systems, DiasNet may be characterised as 'the next generation' of clinical decision support systems, while at the same time integrating a range of patient-centric uses, both as a CAL system as well as a telemedical system supporting registrational, consultational, and supervisional interactivity to support patient empowerment.

Evaluation is defined as the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation) the result of which informs a decision to be made concerning that system in a specific context (Ammenwerth et al., 2004). Concerning the specific context of exploring the quality characteristics of DiasNet, it was implemented as part of the Diabetes Project at the Department of In-

ternal Medicine at Vendsyssel Hospital in Frederikshavn. The aim of the Diabetes Project was to gain experiences about implementing patient-oriented diabetes care systems in general and DiasNet in particular, as well as the system's contribution to the self-care competences of the 11 patients who took part in the project. This aim is understood in terms of two themes, adoption and empowerment, of which the latter is described as a highly controversial issue in diabetes care. Evaluating DiasNet, I thus focus on the system's usefulness in terms of adoption and empowerment.

As a theoretical approach, I chose the school of CHAT, which is suitable for studying both the integration of mediating artefacts (the adoption theme) as well as the development of human activity (the empowerment theme). In choosing this theoretical stance the CID project is thus mainly oriented toward the research field of Human-Computer Interaction, apart from Health Informatics. As opposed to merely studying utility, or traditional usability aspects ('user-friendliness'), 'copability' is coined as a term for a change of focus: to evaluate the DiasNet system's potential in enhancing the user's ability 'to cope' – not with the system itself, as when focusing on user acceptance in a more narrow sense, but with the user's challenges, tasks, or interests as a patient, or as a person. As a methodology the copability approach consists of a collection of methods for an analysis to be carried out in two phases, a descriptive 'interface analysis' together with a normative 'constructive evaluation' of it.

Firstly, for the interface analysis I provide three sets of concepts: Coping types, use forms, and artefact types. The first set of concepts describes the relevant health actions in which DiasNet is used; the concepts about use forms describe the toolness of DiasNet in terms of the patients' typical concerns when using the system; while the third set of concepts is used for categorising the various levels of artefacts – from the physically present artefacts to the stratification of more mentally represented artefacts, which are employed as a part of using DiasNet. On a more detailed account, the concepts are described as follows:

Coping is used as a concept to provide a systematic description of the most relevant aspects of the patients' behaviour and thoughts, i.e., their health actions. In this study, coping means *a diabetes patient's own internal or external actions in order to manage an appraised problem concerning disease management*. This coping definition is mainly inspired by the Lazarus-Folkman (1984) approach. Reviewing examples in the literature on how coping analysis applies to diabetes, it shows that this approach is highly influential, however, mostly in terms of a fundamental distinction between emotion-focused and problem-focused coping. From a more theoretical angle I point out a number of similarities between this approach and CHAT, and I suggest integrating them by viewing coping

processes as an integrated part of human activity. Whereas coping theory provides a detailed analysis of how a stress response unfolds in a breakdown situation, the CHAT approach may provide a deeper analysis into the background of what comes before such breakdown situations in terms of 'unhampered' daily activity. In addition, while the concept of artefacts seems to be missing in the list of personality and environmental variables influencing the process of appraisal as discussed by Lazarus (1999), the CHAT approach supplements the coping analysis with the concept of mediating artefacts. Using open coding procedures I avoided applying coping concepts from the literature when categorising my 'data'. Instead, I began identifying every little chunk of text representing a specific piece of coping behaviour, or 'coping strategy', being employed by one of the patients. Then, I categorised these coping strategies according to a key distinction concerning their coping 'function'. Here, I chose not to use the concepts of emotion-focused and problem-focused coping. Instead, I focused on 'confrontive' or 'distancive' behaviour when a patient is facing disease management problems concerning metabolic control, since this issue is the *raison d'être* of DiasNet as a decision-support system as well as the goal of implementing it as a CAL system. Next, the coping strategies were further categorised in terms of five coping 'forms': Acute internal (emotion-focused) coping, acute external (problem-focused) coping, long-term internal (meaning-focused) coping, and long-term external (routine-focused) coping, as well as contact-focused coping. Each of the five coping forms was found in the two groups of confrontive and distancive coping strategies, resulting in ten different 'types' of coping strategies. While focusing on health actions, a coping analysis does not provide much insight into how DiasNet is integrated as an artefact into the patients' health actions, i.e., how it is used as a tool. But it is on the basis of this analysis that DiasNet's mediation of their health actions is analysed.

Use forms is used as a concept for describing the 'toolness' of DiasNet, being the various ways in which it is mediating the patients' concerns, i.e., their 'objects'. Through open coding, four main concerns were identified: Registration, reflection, exploration and intervention. The first use form was obligatory, while the following three were taken up by the patients by their own initiative. Interestingly, the non-obligatory use forms furthermore seem to match a set of concepts concerning empowerment found in the literature, i.e., Roter's diabetes-related operationalisation of Freire's concepts about three key consciousness raising experiences. The four use forms can be considered various forms of actions, or 'verbs', in which the patients employ DiasNet. Again, the analysis is still not addressing the 'nouns' of the multifaceted toolness of DiasNet in a more detailed manner. However, this is the focus of the final set of concepts.

Types of artefacts refer to a four-layered stratification of artefacts being employed as part of using DiasNet. I study these artefacts not only in terms of primary artefacts (physical 'What' artefacts, including DiasNet), but also in terms of 'How', 'Why', and 'Where-to' artefacts. My analysis of these types of artefacts is founded on a theoretical discussion, which sets out from Engeström's (1987) conflation of three conceptual hierarchies, being concepts of activity, artefacts and learning. I thus provide a critical discussion of Bateson's learning levels in relation to Engeström's own artefact levels (derived from Wartofsky) and Leontiev's activity aspects. The discussion leads to an altered view of the relations between these conceptual hierarchies, as well as to the combination with a fourth set of categories concerning action forms (inspired by Wartofsky).

Next, to carry out an evaluation relating to a specific decision-making context, this descriptive 'interface analysis' is then founding a normative evaluation by relating to the specific goals of implementing DiasNet. The copability analysis thus studies its usefulness in terms of how it is integrated into dealing with diabetes as a part of the patients' everyday lives, both in terms of adoption and patient empowerment. Both issues can be analysed when focusing on each of the three sets of concepts of the interface analysis, as well as – ultimately – when using them in combination. The following accounts for the findings on nine patients' use of DiasNet.

Adoption is, firstly, studied by looking into the coping of the patients. It appears that a large portion (40%) of the coping strategies discussed by the patients a year after the onset of the Diabetes Project is related to DiasNet. This is taken as an indication of adoption, i.e., that the patients have integrated DiasNet as part of their health behaviour, to a fairly large extent. Next, concerning the use forms only registration was obligatory to take part in the Diabetes project. Hence, the mere emergence of the three other use forms is seen as indicating adoption to a considerable extent. Furthermore, each use form appears to be related to many different coping types, indicating that the various approaches to DiasNet appeared in many different health actions. Thirdly, the analysis is looking into the various artefact levels. Concerning What artefacts, it appears that the Input dialogue, the use of SMBG, and mail were adopted to a large extent for registration, being being related to many different coping types. Thus, it seems that it was adopted as a pathway to other more important aspects of the system: the enhanced contact with the clinicians, and the incentive to have an SMBG routine. What also seems to have contributed much to adoption are the facilities to play with own data and to use DiasNet as a mirror. Here, the SMBG curve, the simulated BG curve, and the Future dialogue were widely adopted for reflection, thus exceeding the obligatory use of DiasNet. Concerning the higher-level artefacts – which the pa-

tients have acquired, or developed themselves, as part of using the system – the mere existence of these higher-level artefacts, as well as their distribution, are taken as indications of the amount of work the patients have done to integrate DiasNet into their health activity. What is more, the underlying agenda of the Diabetes Project to encourage self-care thus also seems to have been widely adopted. More on this issue below.

Empowerment is studied from both a medico-centric and a patient-centric perspective. From a medico-centric perspective I suggest that confrontive coping has a higher rank than distancive coping concerning empowerment. Here, CDDM seems to be connected to confrontive coping more closely than to distancive coping. Furthermore, I suggested the following rank concerning coping forms: routine-focused coping, problem-focused, meaning-focused, and emotion-focused coping (contact-focused coping not being included in this list). Thus, concerning coping types being most commonly related to DiasNet it is found that in three confrontive coping types more than half of the passages are related to CDDM, namely routine-focused, problem-focused, and emotion-focused confrontive coping. Hence, it seems that DiasNet primarily has been adopted into the patients health behaviour to support long-term preventive behaviour, acute problem solving, as well as in keeping up a good spirit. This is taken as clear signs of empowerment support form a medico-centric perspective. Also, from a patient-centric perspective, a clear match is noticed between the use forms exceeding the obligatory use and Roter's diabetes-related operationalisation of Freire's concepts on consciousness raising experiences. In particular, the use form reflection instantiates a patient-centric perspective, having emerged from the patients' use of DiasNet and characterising their use of it as a 'mirror' to keep in check of their current condition. Furthermore, it appears that the two coping types, which are topping the rank concerning empowerment, dominated all use forms. As for the What artefacts, these are studied in relation to both use forms and coping types. While the Input dialogue – naturally – is mostly related to the obligatory use form, registration, the others are mostly related to non-obligatory use forms. What is more, all of the What artefacts are mostly related to confrontive coping and mostly the two focal coping types concerning empowerment. On the other hand, a few of them were also to some extent related to types of distancive coping, which are not taken as signs of empowerment. Finally, concerning the higher-level artefacts, in-depth discussions on examples of each sub-category are provided in relation to the learning levels. Their high distribution in the material as well as their instantiations of creative thinking of active and motivated patients are seen as indications of empowerment.

8.2 Resumé på dansk

Copability in Disease Management (CID) er et ph.d.-projekt (2002-5) som led i følgeforskningen under Det Digitale Nordjylland (2000-3), baseret på følgeforskning i Diabetes Projektet, Sygehus Vendsyssel (2003-4), hvor 11 patienter blev introduceret til et computerbaseret patientstøttesystem til diabetikere (DiasNet). Et af de essentielle problemer ved udviklingen og implementeringen af et system som DiasNet er evaluering. CID-projektet fokuserer således på evaluering af DiasNets anvendelighed i forhold til de udfordringer som aktiv patientdeltagelse i behandlingen af diabetes type 1 giver. Imidlertid findes der kun ganske begrænset litteratur om evalueringen af computerbaserede patientstøttesystemer for kronisk syge patienter. Projektet er derfor et eksplorativt og kvalitativt studie, som 1) udvikler en evalueringsmetodologi (*the copability approach*) til beskrivelse af integrationen af patientstøttesystemer i patienters sundhedsadfærd, og evalueringen heraf med henblik på adoption og empowerment, samt 2) leverer en evaluering af DiasNet i overensstemmelse hermed.

Siden resultaterne af DCCT i 1993 har der været megen forskning i måder at anvende ICT til at understøtte intensiv insulinbehandling indenfor diabetes. Et systematisk litteraturreview blev udført angående nylig litteratur om udvikling af ICT systemer inden for behandling af diabetes Type 1 siden afslutningen af DCCT (1994-2004). Dette review viser at lægeorienterede systemer dominerer, til trods for at udviklingen af patientstøttesystemer er efterspurgt. Det viser sig oven i købet overraskende at det blandt systemer til telemedicin er et lavteknologisk transmissionelt system der understøtter empowerment i højere grad end selv to langt mere avancerede supervisionelle systemer (sammenlignelige med DiasNet), der er udviklet til at understøtte 'superviseret autonomi' og 'patientuafhængighed'. Sammenlignet med sådanne systemer kan DiasNet ud fra et medikocentrisk perspektiv karakteriseres som 'fremtidens kliniske beslutningsstøttesystem', mens det samtidig integrerer en række 'patientcentriske' anvendelsesmuligheder, både som et CAL-system og som et telemedicin-system der understøtter registrationel, consultationel og supervisionel interaktivitet til understøttelse af empowerment.

Evaluering er defineret som '*the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation) the result of which informs a decision to be made concerning that system in a specific context*' (Ammenwerth et al., 2004). Angående den specifikke kontekst til udforskningen af kvalitative karakteristika ved DiasNet, blev DiasNet implementeret som led i Diabetesprojektet ved Medicinsk Afdeling, Vendsyssel Sygehus i Frederikshavn. Mål-

sætningen for Diabetesprojektet var at høste erfaringer om implementering af patientrettede systemer indenfor diabetesbehandling, både generelt og om DiasNet i særdeleshed, samt dets indflydelse på egenomsorgskompetencerne hos de 11 patienter der tog del i projektet. Denne målsætning tolkes som bestående af to temaer, adoption og empowerment. Til evalueringen af DiasNet fokuserer jeg således på systemets anvendelighed i forhold til adoption og empowerment, af hvilke sidstnævnte tema beskrives som et yderst kontroversielt emne indenfor behandlingen af diabetes.

Som en teoretisk tilgang valgte jeg virksomhedsteori (CHAT), som egner sig til studiet af både integrationen af medierende artefakter (adoptionstemaet) og udviklingen af menneskelig aktivitet (empowermenttemaet). I valget af dette teoretiske udgangspunkt placerer CID-projektet sig dermed hovedsageligt indenfor forskningsfeltet menneske-maskin-interaktion (HCI), udover sundhedsinformatik. I stedet for blot at undersøge systemets funktionalitet og/eller traditionelle aspekter af 'brugervenlighed', bliver begrebet 'copability' foreslået som koncept for et fokusskift: for at evaluere DiasNet-systemets potentiale til at fremme brugerens evne til at 'cope' – ikke med systemet selv, som når man fokuserer på brugeraccept i en mere snæver betydning, men med sine udfordringer, gøremål og interesser som patient, eller som person. Som en metodologi består copability-tilgangen af en samling metoder for en analyse i to faser, en deskriptiv 'interfaceanalyse' og en normativ 'konstruktiv evaluering' af dette interface.

Til den første fase fremsættes tre begrebssæt til interfaceanalysen: Copingtyper, brugsformer og artefakttyper. Det første begrebssæt beskriver den relevante sundhedsadfærd i hvilken DiasNet anvendes; begreberne om brugsformer beskriver DiasNets redskabelighed i forhold til det som patienterne typisk er optaget af at foretage sig med DiasNet; mens det sidste begrebssæt bruges til at kategorisere en række niveauer af artefakter – fra de fysisk repræsenterede artefakter til en stratifikation af mere mentalt repræsenterede artefakter, som tages i brug som led i det at anvende DiasNet. Mere detaljeret beskrives disse begreber som følger:

Coping bruges som begreb til at sikre en systematisk beskrivelse af de mest relevante aspekter af patienternes adfærd og tanker, dvs. deres sundhedsadfærd. I dette studie defineres coping som '*a diabetes patient's own internal or external actions in order to manage an appraised problem concerning disease management*'. Denne definition er hovedsageligt inspireret af tilgangen hos Lazarus-Folkman (1984). Et review af eksempler på hvordan copinganalyse anvendes indenfor diabetesforskning, viser at denne tilgang er meget indflydelsesrig, dog oftest i form af den grunddistinktionen mellem emotionfokuseret og problemfokuseret coping. Fra en mere teoretisk synsvinkel udpeger jeg en række lighedstræk mellem den-

ne tilgang og CHAT, og foreslår en integration af dem, hvor copingprocesser ses som en integreret del af menneskelig virksomhed. Hvor copingteori giver en detaljeret analyse af hvordan stressrespons ved sammenbrud (breakdown) af hverdagens gøremål, kan CHAT-tilgangen give en mere indgående analyse af baggrunden for disse sammenbrud. Tilmed kan CHAT-tilgangen supplere copinganalysen med en opmærksomhed på medierende artefakter, der tilsyneladende mangler i listen over personlige og miljømæssige variable der har indflydelse på opfattelsen af en situation som stressfuld, sådan som denne proces diskuteres af Lazarus (1999). Gennem 'open coding' undgik jeg at anvende eksisterende copingbegreber i litteraturen i kategoriseringen af mine 'data'. I stedet identificerede jeg til at begynde med enhver lille tekststump i mit materiale der omhandler en specifik copingadfærd, eller 'copingstrategi', hos en af patienterne. Dernæst kategoriseredes alle disse copingstrategier i forhold til en kernedistinktion angående deres coping-'funktion'. Her fravalgte jeg begreberne emotionfokuseret og problemfokuseret coping. I stedet fokuserede jeg på 'konfrontativ' og 'distanciv' adfærd i forhold til at håndtere problemer med at stabilisere blodsukkeret, idet dette er *raison d'être* for DiasNet som beslutningsstøttesystem såvel som målet med at implementere det som CAL-system. Dernæst blev copingstrategierne kategoriseret i forhold til fem coping-'former': Akut intern (emotionfokuseret) coping, akut ekstern (problemfokuseret) coping, langsigtet intern (meningfokuseret) coping og langsigtet ekstern (rutinefokuseret) coping, samt kontaktfokuseret coping. Hver af disse fem copingformer blev fundet i hver af de to grupper af konfrontativ og distanciv coping, hvilket resulterede i ialt 10 forskellige typer af copingstrategier (copingtyper). Da copinganalysen fokuserer på at karakterisere patienternes sundhedsadfærd, giver den ikke megen indsigt i hvordan DiasNet er integreret heri som artefakt, dvs. hvordan det bliver brugt som redskab. Men det er på basis heraf at DiasNets mediering af patienternes sundhedsadfærd analyseres.

Brugsformer bruges som begreb for beskrivelsen af DiasNets redskabelighed i form af dets måder at mediere det som optager patienterne når de bruger systemet, dvs. deres 'objekter'. Gennem 'open coding' identificeredes fire brugsformer: Registrering, refleksion, eksploration og intervention. Den første brugsform var obligatorisk, mens patienterne tog de følgende tre op på eget initiativ. Ydermere havde disse tre en interessant parallel til et begrebssæt fundet i litteraturen angående empowerment, nemlig Roters operationalisering af Freires begreber om de tre bevidsthedsskabende kerneerfaringer. Tilsammen kan de fire brugsformer ses som forskellige former for handlinger, eller 'verber', der beskriver patienternes anvendelse af DiasNet. Analysen var således stadig på afstand af

'navneordene' i forhold til at beskrive DiasNets multifacetterede redskabelighed. Men dette sidste er hvad det sidste begrebssæt fokuserer på.

Artefakttyper som begreb henviser til en firedelt stratifikation af artefakter som tages i anvendelse ved brugen af DiasNet. Jeg undersøger ikke blot de primære artefakter (fysisk forekommende *What*-artefakter, inklusive DiasNet), men også *How*-, *Why* og *Where-to*-artefakter. Min analyse af disse er funderet på en teoretisk diskussion som udspringer af Engeströms (1987) sideordning af tre begrebshierarkier angående menneskelig virksomhed, artefakter og læring. Således præsenterer jeg en kritisk diskussion af Batesons læringsniveauer i relation til Engeströms egne artefaktniveauer (afledt fra Wartofsky) og Leontievs virksomhedsaspekter. Diskussionen munder ud i en anderledes sideordning af disse konceptuelle hierarkier, samt deres kombination med et fjerde set af begreber angående handlingsformer (inspireret af Wartofsky).

Til den næste fase, at udføre en evaluering i forhold til en specifik beslutningskontekst, funderer denne deskriptive 'interface analyse' en normativ evaluering der relaterer til specifikke målsætninger angående implementeringen af DiasNet. Copabilityanalysen studerer således anvendeligheden i forhold til hvordan systemet integreres i patienternes hverdagsliv som diabetikere, både med hensyn til adoption og empowerment. Begge temaer kan analyseres ved at fokusere på hvert af de tre begrebssæt af interfaceanalysen, så vel som – ultimativt – ved at kombinere dem. I det følgende gives en opsummering af fund angående ni patienters brug af DiasNet.

Adoption er i første omgang undersøgt ved at kigge på patienternes coping. Her viser det sig, året efter igangsættelsen af Diabetesprojektet, at en stor del (40%) af patienternes copingstrategier er relateret til DiasNet. Dette tages som udtryk for adoption, altså at patienterne har integreret DiasNet som en del af deres sundhedsadfærd, i en større udstrækning. Dernæst undersøges spørgsmålet angående brugsformer, hvoraf kun en enkelt var obligatorisk. Alene opkomsten af de øvrige ses således som en indikation af en betragtelig adoption. Endvidere forekommer hver brugsform at stå i sammenhæng med mange forskellige copingtyper, hvilket indikerer at de forskellige tilgange til DiasNet optræder i mange forskellige former for sundhedsadfærd. For det tredje kigger analysen på de forskellige artefaktniveauer. Angående *What*-artefakter, ses det at navnlig Inputdialogen, SMBG (det at tage sit blodsukker), samt mails var adopteret i en stor udstrækning og relateret til mange forskellige copingtyper. Den forekommer at være adopteret som en adgang til mere vigtige aspekter af systemet: den forøgede kontakt med klinikerne og tilskyndelsen til at have en SMBG.rutine. Hvad der også ser ud til at have bidraget meget til adoption af systemet er faciliteterne til at lege med egne data og at bruge DiasNet som spejl: SMBG-kurven, den simulerede blodsukkerkur-

ve og Fremtidsdialogen i forhold til brugsformen refleksion, hvilket gik ud over den obligatoriske brig af DiasNet. Angående højniveauartefakterne – som patienterne har tilegnet sig eller selv udviklet som led i anvendelsen af DiasNet – tages deres blotte eksistens, så vel som deres udbredelse i materialet, som udtryk for det arbejde som patienterne har måttet gøre for at integrere DiasNet i deres sundhedsvirksomhed. Hvad mere er, ser denne adoption også ud til at gælde Diabetes Projektets underliggende dagsorden at højne patienternes egenomsorg. Dette er yderligere analyseret i forhold til empowermenttemaet.

Empowerment er studeret fra både et medikocentrisk og et patient-centrisk perspektiv. Fra et medikocentrisk perspektiv foreslår jeg at konfrontativ coping har en højere rang end distanciv i forhold til dette tema. Her forekommer CDDM at være tættere relateret til konfrontativ end distanciv coping. Ydermere foreslår jeg følgende rangordning blandt copingformerne: rutine-, problem-, mening- og emotionfokuseret coping (mens kontaktfokuseret coping ikke er en del af denne rangordning). Angående de copingtyper der oftest er relateret til DiasNet ses det således at ved tre af de konfrontative copingtyper er mere end halvdelen af deres forekomst relateret til CDDM, nemlig rutine-, problem- og emotionfokuseret konfrontativ coping. Det forekommer dermed at DiasNet primært er blevet adopteret i patienternes sundhedsadfærd til at understøtte langsigtet forebyggende adfærd, akut problemløsning så vel som det at holde modet oppe. Dette tages som klare tegn på empowerment fra et medikocentrisk perspektiv. Fra et patient-centrisk perspektiv ses det desuden at der er et klart sammenfald mellem begreberne for de ikke-obligatoriske brugsformer og Roters diabetesrelaterede operationalisering af Freires begreber for bevidstgørende kerneerfaringer. Navnlig instantierer brugsformen refleksion et patient-centrisk perspektiv, idet det er opstået af patienternes egen brug af systemet som 'spejl' til at holde løbende check på egen tilstand. Ydermere ses det at alle brugsformerne er domineret af de to højestrangerende copingtyper hvad angår empowerment. Angående *What*-artefakterne er disse undersøgt i relation til både brugsformer og copingtyper. Mens Inputdialogen – naturligt nok – oftest er relateret til den obligatoriske brugsform, registration, er de øvrige mest relateret til ikke-obligatoriske brugsformer. Hvad mere er, forekommer alle *What*-artefakter oftest at være relateret til de to fokale copingtyper angående empowerment. På den anden side er enkelte af dem også i nogen grad relateret til distancive copingtyper, hvilket ikke tages som tegn på empowerment. Angående højniveauartefakterne diskuteres der endelig en række eksempler for hver underkategori i forhold til læringsniveauerne. Deres store udbredelse i materialet og deres instantiering af kreativ tænkning hos aktive og motiverede patienter ses som tegn på empowerment.

9 Appendices

Appendix A: An overview of the nine patients

Pseudonym	**Sex**	**Birth year**	**Weight Jan.03**	**Weight Autumn 03**	**HbA1c Jan.03**	**HbA1c Autumn 03**
Hans	male	1939	73,2	72,1	7,7	7,6
Connie	female	1963	92,7	90,9	9,9	7,8
Karsten	male	1976	67,0	65,3	9,9	10,4
Bjarne	male	1977	89,2	89,7	8,8	10,8
Bent	male	1968	80,6	-	12,1†)	10,4
Morten	male	1976	68,9	63,1	10,3	9,3*)
Per	male	1945	80,1	79,9	10,3	7,3
Jens	male	1958	-	75,1§)	9,6	9,8
Richard	male	1951	78,3	77,4	8,2	7,3

*) March 2004

†) 25/9/02

§) 10.6.03 (the patient, however, claims to have lost over 10 kg due to the project; cf. Dinesen et al., 2003)

Appendix B: Self-Management Questionnaire

Spørgeskema om egenhåndtering af diabetes type 1[20]

Medicinsk afdeling, afsn. M1, Det Digitale Sygehus
Sygehus Vendsyssel, Frederikshavn

Som led i Diabetes/DiasNet-projektet ved Sygehus Vendsyssel, Frederikshavn, beder vi dig besvare dette spørgeskema. Spørgeskemaet vil blive behandlet som fortroligt materiale.

Udfyld venligst rubrikken om personlige data, og besvar dernæst hvert af de 41 spørgsmål ved at sætte kryds i den boks der bedst beskriver din situation. Hvis der er en kommentarboks, så skriv venligst dit svar heri. Hvis du vil ændre et svar, så udstreg venligst det 'forkerte' svar og skriv det nye svar i marginen. Send dernæst spørgeskemaet til:

Medicinsk afdeling, afsn. M1
Sygehus Vendsyssel
Barfredsvej 83
9900 Frederikshavn
Att.: Sekretær Mette Birkkjær

På forhånd tak.

Navn:	Fødselsdato:
Adresse:	Køn: M ☐ K ☐
	Hvilket årstal blev du diagnosticeret:

1: Oplever du at du har tilstrækkelig viden om din diabetesbehandling og dens gavnlighed?

Jeg vil gerne vide meget mere	*Jeg vil gerne vide lidt mere*	*Jeg ved næsten nok*	*Jeg ved nok til mit behov*	*Jeg ved mere end rigeligt*
☐	☐	☐	☐	☐

2: Hvilket blodsukkerniveau (mmol/l) er efter din mening tegn på god diabetes-kontrol? (Afkryds evt. flere bokse)

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

3: Hvilket blodsukkerniveau har du selv som målsætning? (Afkryds evt. flere bokse)

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

4: Hvor ofte i den sidste halvanden måneds tid tror du at dit blodsukkerniveau har ligget inden for din målsætning?

Aldrig	*Sjældent*	*Noget af tiden*	*Som oftest*	*Hele tiden*
☐	☐	☐	☐	☐

[20] Dansk oversættelse af 'IDDM Diabetes Self-Management Questionnaire, Ipswich Diabetes Center' er udarbejdet af Ph.D-stud. Egil Boisen, Institut for Sundhedsteknologi, Aalborg Universitet, januar 2003

5: **Hvor god synes du at din diabetes-stabilisering har været i samme periode?**

Meget dårlig	*Dårlig*	*Acceptabel*	*Ret god*	*God*
☐	☐	☐	☐	☐

6: **Hvor tilfreds er du med din aktuelle diabetes-stabilisering?**

Meget tilfreds	*Tilfreds*	*Den er OK*	*Ønsker forbedring*	*Ønsker stor forbedring*
☐	☐	☐	☐	☐

7: **Når du har det godt, hvor ofte måler du så dit blodsukker? (Sæt kun ét kryds).**

Hver dag		En gang hver fjortende dag	
4 til 6 dage om ugen		En gang om måneden	
2 til 3 dage om ugen		Mindre end en gang om måneden	
1 dag om ugen		Bruger hovedsageligt urintests	

Andet	

Kommentar:

8, a: **På en dag hvor du måler dit blodsukker, hvor mange gange måler du det så?**

8, b: **På hvilke tidspunkter måler du typisk dit blodsukker? (Sæt gerne flere krydser).**

Før morgenmåltidet		Før aftensmåltidet	
Midt på formiddagen		Midt på aftenen	
Før frokost		Før sengetid	
Midt på eftermiddagen		På forskellige tidspunkter	

Andet	

Kommentar:

9: **Hvor meget synes du at blodsukkermålingerne hjælper dig til at få kontrol over din diabetes?**

Meget	*Noget*	*En smule*	*Næsten ikke*	*Slet ikke*	*Ved ikke*
☐	☐	☐	☐	☐	☐

10: **Hvis du følte behov for det, hvor ofte ville du så tilpasse din insulindosis på egen hånd fremfor at kontakte læge eller sygeplejerske?**

Gør det aldrig selv	*Sjældent*	*Undertiden*	*Meget ofte*	*Gør det altid selv*
☐	☐	☐	☐	☐

11: **Hvis du selv skulle foretage ændringer i din indulindosis, hvor tryg ville du da føle dig i forhold til om ændringerne ville have den ønskede effekt?**

Meget tryg	*Tryg*	*Nogenlunde tryg*	*Ikke særlig tryg*	*Meget utryg*
☐	☐	☐	☐	☐

12: **Hvor ofte finder du det problematisk at tage din insulin på det anbefalede tidspunkt?**.

Meget ofte	*Ofte*	*Undertiden*	*Sjældent*	*Aldrig*
☐	☐	☐	☐	☐

13: **Hvor ofte oplever du at det er vanskeligt at tilpasse din insulindosis ud fra din blodsukkermåling?**

Meget ofte	*Ofte*	*Undertiden*	*Sjældent*	*Aldrig*	*Sker aldrig*
☐	☐	☐	☐	☐	☐

14: **Hvor ofte har du en form for ID på dig der viser at du har diabetes?**

Aldrig	*Nogle gange*	*Som oftest*	*Næsten altid*	*Altid*
☐	☐	☐	☐	☐

15: **I hvor høj grad er det efter din mening besværet værd at have god kontrol med din diabetes?**

Overhovedet ikke	*I ringe grad*	*I nogen grad*	***I høj grad***	*I meget høj grad*
☐	☐	☐	☐	☐

16,a: **Hvor meget påvirker det dit familieliv at tage hensyn til din diabetes?**

Ingen påvirkning	*En smule*	*En del*	*En hel del*	*Meget*
☐	☐	☐	☐	☐

16,b: **Hvor meget påvirker det dine hverdagsaktiviteter (såsom arbejde, børnepasning, studier, husligt arbejde, jobsøgning osv.) at tage hensyn til din diabetes?**

Ingen påvirkning	*En smule*	*En del*	*En hel del*	*Meget*
☐	☐	☐	☐	☐

16,c: **Hvor meget har hensynet til din diabetes indflydelse på ferier og rejseplaner?**

Ingen påvirkning	*En smule*	*En del*	*En hel del*	*Meget*
☐	☐	☐	☐	☐

17: **Hvordan forholder du dig til de eventuelle livsstilsændringer som følge af din diabetes?**

Fuldt acceptable	*Acceptable*	*Lige akkurat acceptable*	*Uacceptable*	*Komplet uacceptable*
☐	☐	☐	☐	☐

18: **Hvor ofte får du støtte af familie, venner og kolleger i forhold til at tage hensyn til din diabetes, eksempelvis ved at de udviser tålmodighed når du skal bruge tid på at tage blodsukkermålinger?**

Aldrig	*Sjældent*	*Indimellem*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

19: **Hvor ofte råder andre dig til at tage en blodsukkermåling?**

Aldrig	*Sjældent*	*Indimellem*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

20: **Hvor ofte oplever du at andre blander sig i din diabetes-håndtering?**.

Aldrig	*Sjældent*	*Undertiden*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

21: **Hvor ofte giver diabetes dig bekymringer over dit helbred på langt sigt?**

Aldrig	*Sjældent*	*Undertiden*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

22: **Hvor ofte har du negative følelser, såsom skyldfølelse, generthed og vrede, i forbindelse med diabetes?**

Aldrig	*Sjældent*	*Undertiden*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

Du er muligvis opmærksom på at en dårligt stabiliseret diabetes kan føre til komplikationer såsom hjerte-kar-sygdomme og skader på øjne og nyrer.

23: **I hvor høj grad er du bekymret for at du selv kan få sådanne komplikationer?**

Bekymrer mig slet ikke	*Tænker på det sommetider*	*Ret bekymret*	*Meget bekymret*	*Meget bange*
☐	☐	☐	☐	☐

24: **Hvor tryg er du ved at god kontrol med diabetes kan forebygge eller udsætte sen-komplikationer?**

Meget tryg	*Tryg*	*Nogenlunde tryg*	*Ikke særlig tryg*	*Meget utryg*
☐	☐	☐	☐	☐

25: **Hvor ofte oplever du at det at have kontrol med din diabetes stiller urimeligt store krav til dig?**

Aldrig	*Sjældent*	*Undertiden*	*Ofte*	*Hele tiden*
☐	☐	☐	☐	☐

26: **Hvilke ændringer i din diabetes-håndtering vil du typisk foretage når du er syg?** (Sæt gerne flere krydser)

Ingen		Indtager mere væske	
Tager flere blodsukker- og urinmålinger		Indtager mere sukker i frugtjuice, sportsdrik eller andet	
Fortsætter min normale insulindosis		Ringer til min læge	
Reducerer min insulindosis		Ved ikke	
Forøger min insulindosis i overensstemmelse med målinger		Skærer ned på mad og drikke	
Prøver at spise mere		Andet	

Kommentar:

27:	**Hvor tryg er du ved din egen evne til at tage vare på dig selv når du ikke har det godt?**				
	Meget tryg	*Tryg*	*Nogenlunde tryg*	*Ikke særlig tryg*	*Meget utryg*
	☐	☐	☐	☐	☐
28:	**Oplever du at det er nemt at følge retningslinjerne angående diæt?**				
	Aldrig	*Sjældent*	*Indimellem*	*Ofte*	*Hele tiden*
	☐	☐	☐	☐	☐
29:	**Hvad mener du om anbefalingerne angående diæt for diabetespatienter?**				
	Skaber ingen problemer	*Undertiden begrænsende*	*Ret begrænsende*	*Restriktive*	*Meget restriktive*
	☐	☐	☐	☐	☐
30:	**Hvor tryg er du ved din egen evne til at vurdere indholdet af kulhydrat i den mad du spiser?**				
	Meget tryg	*Tryg*	*Nogenlunde tryg*	*Ikke særlig tryg*	*Meget utryg*
	☐	☐	☐	☐	☐
31:	**Føler du dig tryg ved at ændre mængden af kulhydrat i den mad du spiser?**				
	Meget tryg	*Tryg*	*Nogenlunde tryg*	*Ikke særlig tryg*	*Meget utryg*
	☐	☐	☐	☐	☐
32:	**Oplever du at du er:**				
	Undervægtig	*Normalt slank*	*Lidt for tyk*	*Overvægtig*	*Meget overvægtig*
	☐	☐	☐	☐	☐
33:	**Hvor tilfreds er du med din aktuelle vægt?**				
	Yderst tilfreds	*Tilfreds*	*Den er OK*	*Ønsker forandring*	*Ønsker stor forandring*
	☐	☐	☐	☐	☐
34:	**Hvor ofte ændrer du din insulindosis på grund af bekymringer angående din vægt?**				
	Aldrig	*Sjældent*	*Undertiden*	*Ofte*	*Meget ofte*
	☐	☐	☐	☐	☐

35: **Hvilke ændringer foretager du typisk i din diabetes-håndtering, hvis du skal udføre ekstra meget fysisk aktivitet (eksempelvis sportsaktiviteter eller tungt havearbejde)?** (Sæt gerne flere krydser)

Ingen		Spiser mindre	
Spiser en ekstra snack forinden (f.eks. Mars-bar, kiks)		Stopper efter en times tid for at få noget at spise	
Spiser ekstra mad (f.eks. sandwich)		Spiser efter motionen	
Reducerer min insulin forud for motionen		Ved ikke	
Tester mit blodsukker forud for motionen		Tager mere insulin før motionen	
Tester mit blodsukker efter motionen		Andet (skriv kommentar)	
Kommentar:			

36: **Hvor sikker er din vurdering af om en hypoglykæmi er på vej?**

Har aldrig haft en hypoglykæmi | *Usikker* | *Ret sikker* | *Sikker* | *Meget sikker*

☐ ☐ ☐ ☐ ☐

37: **Cirka hvor ofte oplever du hypoglykæmier?** (Sæt venligst kryds ud for din gennemsnitlige frekvens eller skriv et svar i kommentarboksen).

Oftere end tre gange ugentligt		En gang i kvartalet	
1 – 3 gange om ugen		1 – 3 gange årligt	
1 – 4 gange om måneden		Der går år imellem	
Aldrig		Andet (skriv kommentar)	
Kommentar:			

38: **Hvor bange er du ved tanken om det at få en hypoglykæmi?**

Slet ikke bange | *Urolig* | *Ret bekymret* | *Meget bekymret* | *Meget bange*

☐ ☐ ☐ ☐ ☐

39: **Oplever du at det er nødvendigt at have let forhøjede blodsukkerværdier for at undgå hypoglykæmier?**

Meget ofte | *Ofte* | *Undertiden* | *Sjældent* | *Aldrig*

☐ ☐ ☐ ☐ ☐

40: **Hvor tryg føler du dig ved din evne til at undgå hypoglykæmier?**

Meget tryg | *Tryg* | *Nogenlunde tryg* | *Ikke særlig tryg* | *Meget utryg*

☐ ☐ ☐ ☐ ☐

41: **Hvor tryg føler du dig ved din evne til at håndtere en hypoglykæmi?**

Meget tryg | *Tryg* | *Nogenlunde tryg* | *Ikke særlig tryg* | *Meget utryg*

☐ ☐ ☐ ☐ ☐

Appendix C: Interview guide – example

'Bent' 26/4-2004, hjemme hos Bent kl. 13.00 – 15.07

- **Hverdagssituation:** kan du beskrive din hverdag, dit arbejde; familieliv, sociale liv, fysisk aktivitet.
- **Diabetesprojektforløb, iøvrigt**
  - Diabeteskolen: dialog med ptt; stoffet; undervisningsformen
  - har du savnet feedback, hurtigere opfølgning?
  - støtte/ overvågning?
  - udsættelse af evalueringsmøderne
  - tekniske vanskeligheder.
  - DiasNet vs ambulante kontroller hver tredje måned; kommunikation med PRO.
  - hvad er svært, hvad er nemt?
  - Hvad kan gøres anderledes?
  - hvad forventer du dig af fremtiden: ift. projektet/ medpatienter
- **self-management FØR ~ NU ift. diabetes-hverdag (adfærd, oplevelse af diabetes, livskvalitet)**
  - IPSWICH jan03 – april04:
    - målsætning – forøget?
    - hypoer: taget til?
    - egenmonitorering: uforandret.
    - acceptance: negativ forandring ift. påvirkaning af familieliv.
      - hvad med ferier?
    - cost-benefit: klar forværring- livsstilsforandringer er uacceptable, og Peter er kun nogenlunde tryg ved at kunne forhindre senkomplikationer.
    - emotional adjustment:
      - oplever ofte at diabetes stiller urimeligt store krav (og uacceptabel livsstil); men aldrig nogen negative følelser?
      - aldrig bekymret over sen-komplikationer ('hele tiden' jan03) og bekymrer sig slet ikke ('meget bange' jan03) – placerer sig i den anden ende af skalaen.
      - er det frustrerende at tænke at god kontrol kan forebygge senkomplikationer, og hele tiden være bange for dem, og så samtidig have vanskeligheder med at opnå god stabilisering.

- ❖ self-efficacy: næsten det samme, men klar forbedring omkring oplevelsen af hvor meget BG hjælper; siger at han ved 'mere end rigeligt' – spørg ind.
  - o tidligere skrev du at BG ikke opleves at give mere end en smule hjælp? hvad bruges BG til for dig? Hvordan skal der ellers opnås god kontrol?
  - o vide nok til sit behov – og samtidig have vanskeligheder?
  - o vide mere end rigeligt?
  - o meget mindre tryg ved kulhydrat og effekten?
- ❖ Skills: utydeligt, men det ser ikke godt ud.
  - o tilpasse insulin: hvordan vurderer du om dine injiceringer har den ønskede effekt?
  - o hvad gør du ved sygdom?
- ❖ hvilke senkomplikationer har du haft?

- o kulhydrater; spiser du anderledes i dag; tænker du anderledes omkring mad?
- o insulinjusteringer; hvornår kan det være problematisk at tage insulin.
- o mere sikker føling – er der sket nogen forandring i perioden?
- o Hvordan har du taklet den 'anderledeshed' som følger med at have diabetes?
- o Hvilke ændringer er der sket i den måde din diabetes er håndteret på siden da?
- o kommer der et tidspunkt hvor man bliver 'voksen som diabetiker' (ift. lægen eller andre)?
- o Michael-citat: 'diabetespatient-eksperten er ikke den der lever op til regimet til punkt og prikke' – vil du kommentere dette?
- o hvad synes du om empowerment-tankegangen ansvar for egen sundhed?
- o hvad ville du sige til en ung fyr der lige har fået diabetes?

DiasNet: brugsmønster og hverdag - DATID

- o hvornår brugte du typisk DiasNet?
- o hvor tilgik du det og hvor lang tid tager det?
- o nedfælder du dine målinger på papir?
- o hvor lang tid tog det at blive fortrolig med? Kan du det du gerne vil kunne?
- o hvordan bruger du det? (Forskningsspørgsmål: Indrapportering, beslutningsstøtte, læringsværktøj)

❖ Brugs-rytme:

- begynder 25/2-03 – stopper: 28/9-03
- ugentligt (3 dage): jan/feb03 ..
- 3 gange månedligt: mar, apri (nogle enkeltdage), maj, juni
- derefter: 2 gange i juli, en gang i september

❖ generelt indtryk
- i starten variende filnavne – vanskeligt at gemme i starten?
- 4 BG i hele perioden
- ret flittig, rytmisk aktivitet, men ebber ud efter en sommerferie
- tiltider ret varierende måltider, men ellers fast spisetider og fast morgenmad
- højtliggende, ind i mellem meget små udsving, ind i mellem ret store
- til tider meget høj risiko

❖ Forandringer
- HbA_{1c}: jan03 ?? til sep03 10,4 – den første? Hvad tænker du om det?
- Det ser ikke ud til at du lev nedreguleret?
- kan du nævne: GODE PERIODER, VANSKELIGE PERIODER.

❖ FORLØB:
- jan03: rytmisk insulin; varierende mad; 4 BG/rytmisk; meget høje om aftenen og ret lave værdier til formiddag/ middag;
- startfeb03: samme billede uden de lave.
- midt feb03: meget små udsving; højtliggende
- ...
- kommenter 29juni + 11juli (rytmisk ratio men højtliggende)

❖ **COPING:**
- beskriv en vanskelig situation i sidste uge, hvad gør du, hvad tænker og føler du? – hvad ville du have gjort tidligere?
- hvad tænker du om senkomplikationer?
- Tænker du tit på hvordan dit liv ville have været uden diabetes? Hvordan ville det have været?
- oplever du diabetes som en sygdom?

❖ **MOTIV:**
- spørge ind til frygt (akutte og senkomplikationer);
- 'disheartening' oplevelser/ frustrationer
- inspiration/ fornyet energi.

Checket ift. Hallberg, Lundmann, Hofgreen, Laila (hos Bibi).

Appendix D: Four artefact levels – examples

Artefact levels and action forms	**Engeström** (1987; 1990)	**Music**	**Car driving**
What artefacts - and primary actions (Learning 0)	Looking up *data* in *files* on *test findings.*	Playing an *instrument* using a *score/ nodes* as stimuli	Handling a *gear knob* and a *steering wheel.* Noticing *traffic signals.*
How artefacts - and secondary actions reflecting on means and conditions (Learning 1)	Following *instructions* concerning computer use or treatment. Finding a *way* of balancing blocks through trail and error, 'action response'.	Putting *marks in the score* according to a conductor's *instruction*s concerning interpretation of '*passages*' (minor contexts) within the composition. Rehearsing the *score*.	Following *a route* on an electronic navigation system. Following an *instruction* to avoid blocking the brakes. Taking account of *foreign traffic signals.*
Why artefacts - and tertiary actions reflecting on goals (Learning II)	Finding a *meaningful pattern* to explain a certain patient situation. Setting the goal to build up an *explanatory model* to explain when the blocks will balance or not, 'theory response'.	Setting the goal to understand a *composition* as a whole (the overall context of the minor passages). *Stories* about the musical intentions behind a composition or an *interpretation* of it.	Taking account of *explanatory models* about tire friction when rehearsing *optimal driving techniques*. Setting the goal to device an *ABS*, or *ESP* system.
Where-to artefacts - and quartenary actions reflecting motive (Learning II- III)	Defining new *codicies* to guide behavior. Employing *YE's triangle model* to guide *ongoing discussions* on problematic work practices.	Engaging in an ongoing debate on music as an art form by presenting *visions* verbally.	To arrange *racing competitions on closed tracks* to stop dangerous driving on public roads as a subcultural actvity among fellow youngsters.

Appendix E.1: Primary Artefacts in CDDM

Data dialogue:

SMBG graph (9/41)

ProbConfReflec (8), EmoConfReflec (6), RoutConfReflec (6).

BG simulation (9/19):

ProbConfReflec (5), EmoConfReflec (5), ProbConfInt (2).

Mail (9/22)

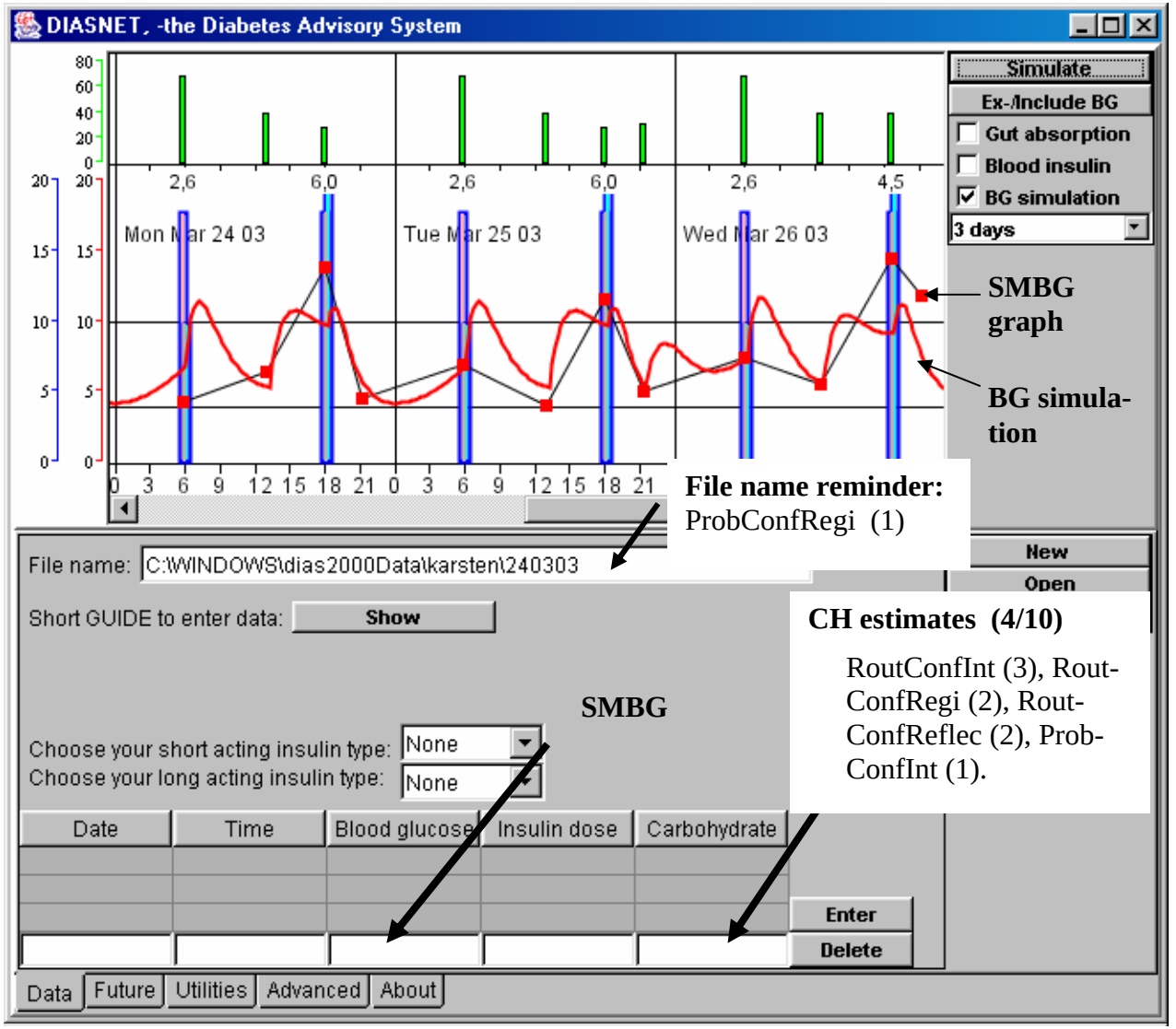
ContConfRegi (7), ProbConfRegi (6), Emo-DistRegi (3), EmoConfRegi (2), MeanConfRegi (2), RoutConfRegi (1).

Input dialogue (9/70)

ProbConfRegi (8), RoutConf-Regi (8), ContConfRegi (6), MeanConfRegi (6), EmoDist-Regi (5), EmoConfRegi (4), ProbDistRegi (3).

SMBG (9/60)

ProbConfRegi (7), RoutConf-Regi (7), EmoConfRegi (5), ProbConfInt (5), RoutConfInt (5), Emo-DistRegi (5), ContConfRegi (1).



Appendix E.2: Primary Artefacts in CDDM

Ratio (1/1)

ProbConfReflec (1), Emo-ConfReflec (1).

Two horizontal lines (1/2):

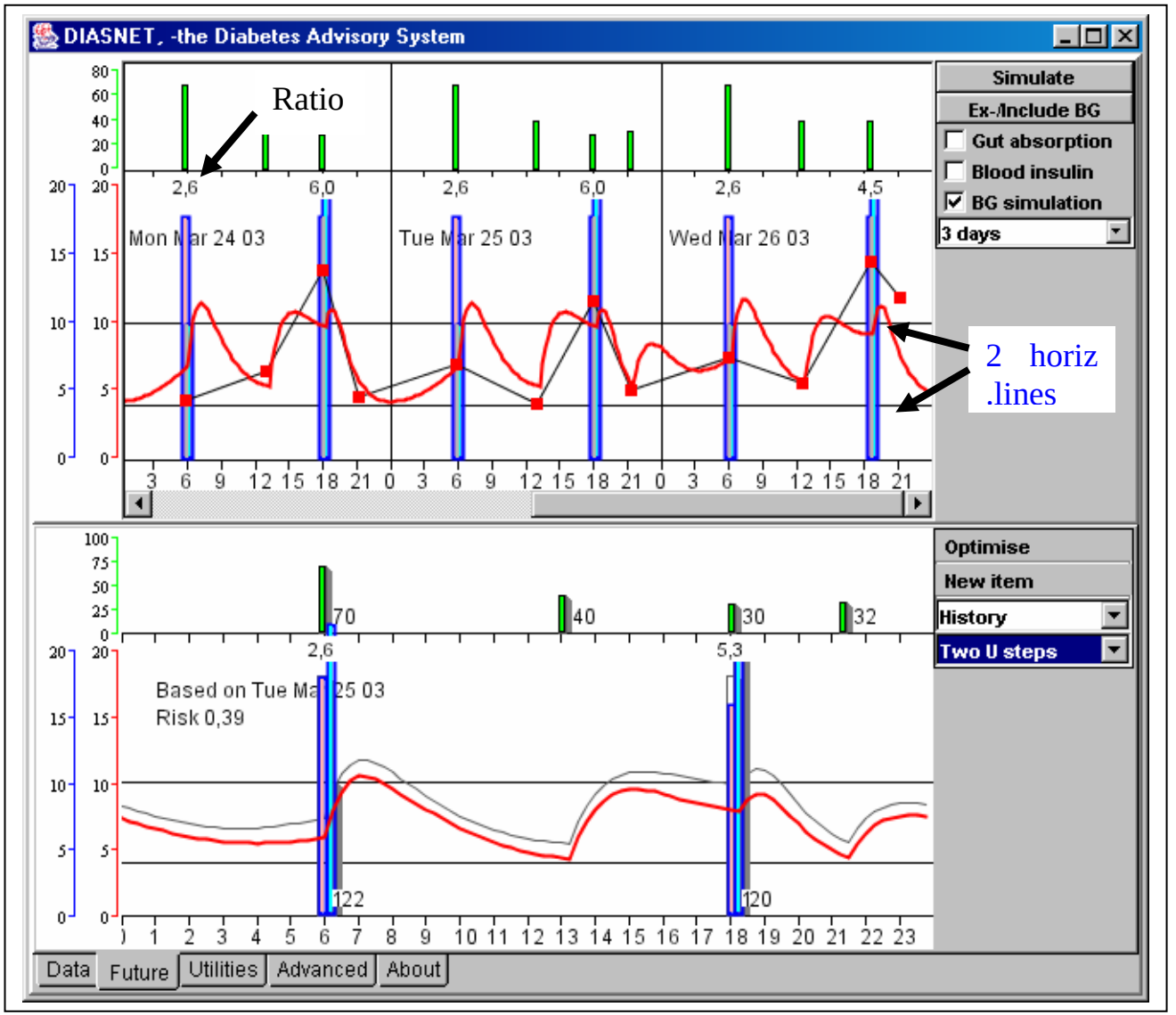
ProbConfReflec (1), Emo-ConfReflec (1).

Future (8/39)

ProbConfInt (5), RoutConf-Explore (5), RoutConfInt (5), EmoConf-Int (5), ProbConf-Reflec (1), RoutConfReflec (1).

Risk (1/2):

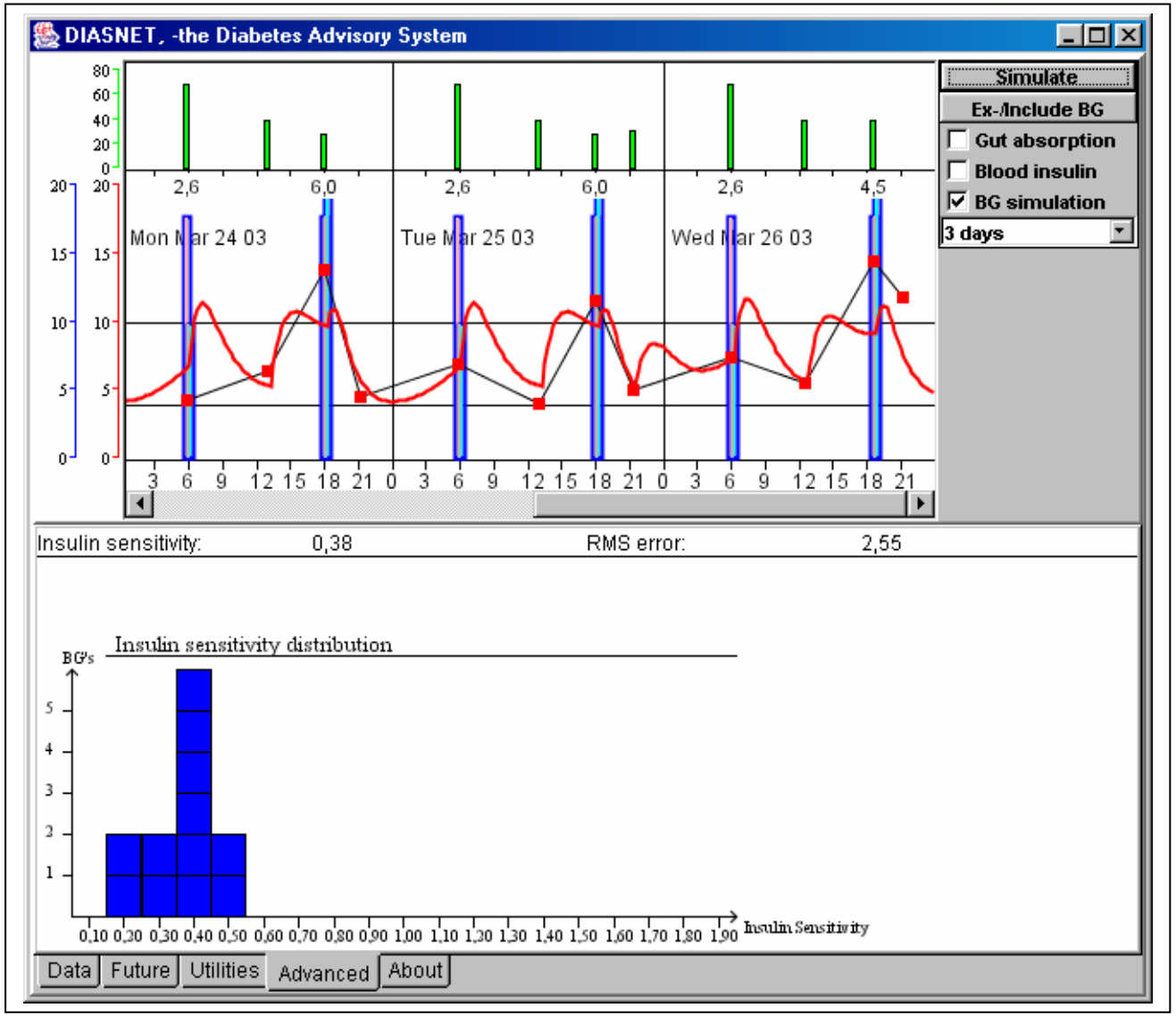
ProbConfReflec (1), Emo-ConfReflec (1).



Appendix E.3: Primary Artefacts in CDDM

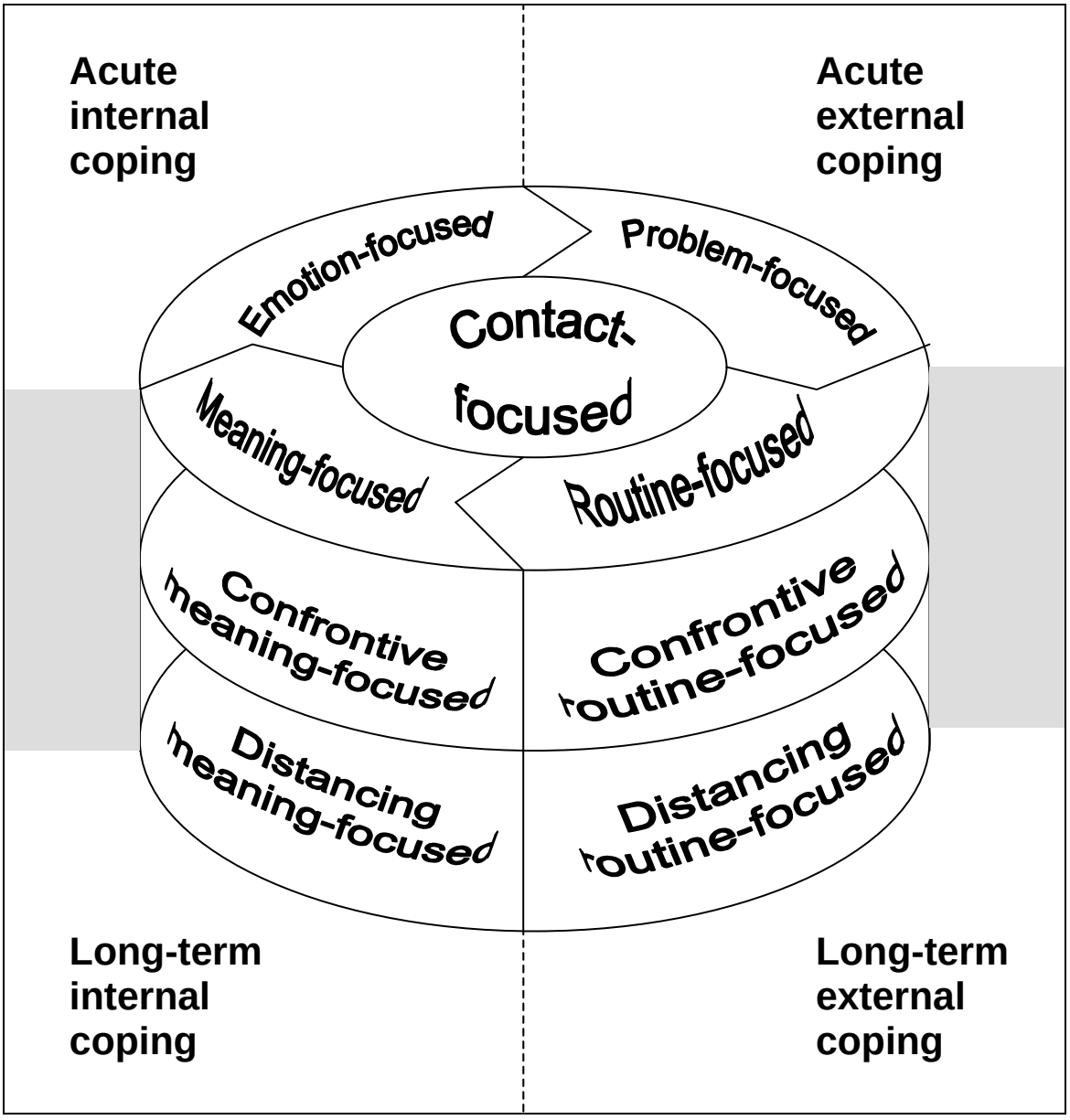
Insulin Sensitivity (IS) (3/7)

ProbConfReflec (2), Emo-ConfReflec (1), RoutConfRe-flec (1), RoutConf-Explore (1).



Appendix F: A diabetes coping cylinder

Diabetes coping forms and functions: Two cycles[21]



[21] The cylinder model provides an overview of all 10 coping types, as its 'predecessor', the cube structure being presented in Chapter 4, does not include contact-focused coping. The cylinder results from placing the fifth coping form in the centre of the cube. This illustrates that contact-focused coping may serve as a vehicle for the other coping forms. However, the resulting model also – prematurely – suggests a certain dynamic relationship between the coping forms (the arrows between them) in terms of a learning process through four phases, from emotion-focused to meaning-focused, through problem-focused, and routine-focused coping. I do not provide an analysis to further expand on this idea. The model was therefore not included in Chapter 4.

Appendix G: List of abbreviations

(Technical terms and names of institutions, only)

ATT39:	scale assessing emotional adjustment in diabetic patients
BG:	blood glucose (measurements)
CAL:	computer assisted learning
CH:	carbohydrate (estimates)
CAQDAS:	computer assisted qualitative data analysis software
CHAT:	The school of Cultural Historical Activity Theory
CDDM:	computerized diabetes disease management
COPE:	scale assessing coping strategies
CPN:	causal probabilistic network (or Bayesian network)
DCCT:	The Diabetes Control and Complications Trial
DESG:	Diabetes Education Study Group
DDN:	Det Digitale Nordjylland (Digital North Denmark)
DDS:	Det Digitale Sygehus (The Digital Hospital)
DM:	disease management
DMAA:	Disease Management Association of America
EMR:	electronic medical record
EPR:	electronic patient record
HbA_{1c}:	glycosylated haemoglobin (an indicator of the average recent BG level)
HCI:	human-computer interaction
HMO:	health maintanance organisation
ICT:	information and communication technology (not, islet cell transplantation)
IDDM:	insulin-dependent diabetes mellitus
IIT:	intensive insulin therapy
IS:	insulin sensitivity
ISF:	electronic interstitial fluid (sensors)
IVR:	interactive voice response (telephone-based)

Appendix G: List of abbreviations (Contd)

MBR:	model-based reasoning
MeSH	controlled vocabulary used for indexing articles for MEDLINE/ PubMed
MMB:	multi modal-based (reasoning)
MU:	medical unit
NHP	intermediate-acting insulin
NTS:	negotiated telephone support
pass:	passages
pts:	patients
PU:	patient unit
RBR:	rule-based reasoning
RCT:	randomized, controlled trial
SMBG:	self-monitoring of blood glucose